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**Exploring the Social Context of Dementia Caregiving:
Emotions and Identities**

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A thesis submitted in part fulfilment of the requirements for the degree of
Doctor of Clinical Psychology

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Contents

List of tables and figures	7
List of abbreviations.....	8
List of appendices	9
Acknowledgements	10
Declaration	11
Summary	12

Chapter 1: Literature Review

‘The Self-Conscious Emotions of Guilt and Shame in Family Caregivers of People with Dementia: A Systematic Review of the Literature’

1.1. Abstract	14
1.2. Introduction	15
1.2.1. Background	15
1.2.2. Caregiving and dementia	15
1.2.3. Dementia and social relationships.....	16
1.2.3.1. The care dyad	16
1.2.3.2. The dementia caregiver	17
1.2.4. Self-conscious emotions	18
1.2.5. Guilt, shame and clinical symptoms	19
1.2.6. Guilt, shame and caregiving.....	20
1.2.7. Rationale	20
1.2.8. Aim of the current review	21
1.2.9. Research question.....	21
1.3. Method	22
1.3.1. Search strategy	22

1.3.2. Data sources	22
1.3.3. Selection criteria.....	23
1.3.3.1. Inclusion criteria.....	23
1.3.3.2. Exclusion criteria	24
1.3.4. Manual search	24
1.3.5. Search results	24
1.3.6. Assessment of quality	26
1.3.6.1 Reliability of quality ratings	26
1.3.6.2. Summary of quality assessment.....	27
1.3.7. Data extraction and synthesis.....	28
1.3.8. General study characteristics	28
1.4. Results	35
1.4.1. Relationship context.....	35
1.4.1.1. Relationship to person with dementia	35
1.4.1.2. Wider social relationships.....	37
1.4.1.3. Gender difference.....	37
1.4.2. Protective factors and vulnerabilities	38
1.4.2.1. Coping.....	38
1.4.2.2. Clinical presentation of caregiver	39
1.4.2.3. Links to other self-conscious emotions.....	41
1.4.3. Impact of Behavioural symptoms and behavioural expression.....	42
1.4.3.1. Impact of shame on relationships.....	42
1.4.3.2. Impact of guilt on relationships.....	43
1.4.4. Negative feelings towards the person with dementia.....	44
1.4.5. Progression of illness	45

1.4.5.1. Guilt over long-term care	45
1.4.5.2. Feelings of failure in relation to an experience of guilt ..	47
1.4.5.3. Cognitive dissonance	47
1.4.6. Sense of responsibility	48
1.4.6.1. Responsibility for others	48
1.4.6.2. 'Breaking promises'	49
1.5. Discussion	50
1.5.1. Discussion of findings.....	50
1.5.1.1. Vulnerable groups	50
1.5.1.2. Clinical presentation	50
1.5.1.3. Impact of guilt and shame	51
1.5.1.4. Conceptualisation.....	52
1.5.1.5. Methodology issues.....	53
1.5.2. Research implications	54
1.5.3. Clinical implications	55
1.5.3.1. Clinical assessment	55
1.5.3.2. Clinical intervention.....	55
1.5.4. Limitations of the current review	57
1.5.5. Conclusions	59
1.6. References	60

Chapter Two: Empirical Paper

'The Construction of Identity in Dementia Caregivers Contributions to an Online Support Forum: A Discourse Analysis'

2.1. Abstract	72
---------------------	----

2.2. Introduction	73
2.2.1. Dementia	73
2.2.2. Dementia care.....	74
2.2.3 Discursive psychology	75
2.2.4. Discourse and society.....	76
2.2.5. Discourse and identity	77
2.2.6. Rationale	80
2.2.7. Aim	81
2.2.8. Research question.....	81
2.3. Methodology	81
2.3.1. Ethics.....	81
2.3.2. Everyday interaction	82
2.3.3. Online support forums	83
2.3.4. Data corpus.....	83
2.3.5. Selection of data.....	84
2.3.6. Conducting the analysis	85
2.4. Analysis.....	86
2.4.1. ‘Fragile self’	87
2.4.2. ‘Fighter self’	94
2.4.3. ‘The Fragile self’ responds to ‘The Fighter self’	99
2.5. Discussion	102
2.5.1. Summary of the findings.....	102
2.5.2. Discussion relating to the literature.....	102
2.5.3. Methodological limitations.....	105
2.5.4. Future directions.....	106

2.5.5. Implications for clinical practice.....	107
2.5.6. Conclusion	109
2.6. References	110

Chapter Three: Reflective Paper

‘Reflections on the challenges of conducting research as a mother’

3.1 Abstract	119
3.2. Introduction.....	120
3.3. Transitions.....	120
3.4. Multiple identities	121
3.4.1. Moral dimensions.....	121
3.4.2. Competition.....	122
3.4.3. Co-construction of identity	123
3.5. Guilt and shame.....	123
3.5.1. Impact of behavioural expression	123
3.5.2 Negative feelings towards cared for.....	124
3.6. Reciprocity	125
3.7. Dependency.....	126
3.8. Protective factors.....	127
3.8.1. Emotional containment	127
3.8.2. Self management.....	128
3.8.3. Time for reparation	128
3.9. Conclusions.....	129
3.10. References.....	129

List of Tables

Table 1.1	Search terms based on the review question	22
Table 1.2	General study characteristics	29

List of Figures

Figure 1.1	Flow diagram presenting the study selection process	25
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List of Abbreviations

AD	Alzheimer's disease
APA	American Psychiatric Association
BRS	Behaviour Rating Scale
CAPE	Clifton Assessment Procedures for the Elderly
CES-D	Center for Epidemiological Studies-Depression Scale
CGQ	Caregiver Guilt Questionnaire
DoH	Department of Health
DSM	Diagnostic and Statistical Manual
FS-AD	Family Stigma in Alzheimer's Disease
IAA	Iran Alzheimer's Association
ONS	Office for National Statistics
POMS	Profile Of Mood States
PSQ	Psychosocial Support Questionnaire
PwD	People/Person with Dementia
WHO	World Health Organisation
ZBI	Zarit Burden Interview

List of Appendices

A	Author instructions for ' <i>Clinical Psychology Review</i> '	131
B	Author instructions for ' <i>British Journal of Psychology</i> '	137
C	Author instructions for ' <i>Reflective Practice</i> '	141
D	Original quality framework	143
E	Flowchart representing amended quality framework	144
F	Guidelines for quality assessment- Quantitative	145
G	Guidelines for quality assessment- Qualitative	146
H	Quality assessment scores for each paper- Quantitative	147
I	Quality assessment scores for each paper- Qualitative	148
J	Research proposal to Alzheimer's Society	149
K	Ethical Approval from Alzheimer's Society	154
L	Ethical Approval from Coventry University	155
M	Extract from discussion forum thread	156

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Thank you

Declaration

This thesis was carried out under the academic supervision of Dr Lesley Pearson (Clinical Tutor at the Coventry and Warwick Clinical Psychology Doctorate) and under the clinical supervision of Dr Sarah Major (Clinical Psychologist at Coventry and Warwickshire Partnership Trust) and Jane Muers (Clinical Psychologist). Dr Simon Goodman (Senior lecturer at Coventry University) supervised the methodology of the empirical paper.

Apart from these collaborations I can confirm that the intellectual content of the work is the result of my own efforts and of no other person. This work, or any part thereof, has not been submitted for a degree to the University or any other institution.

The nominated journals for publication of chapters 1, 2 and 3 are: Clinical Psychology Review, British Journal of Psychology, and Reflective Practice, respectively (see Appendices A - C for instructions to authors). Authorship of any publications arising from this thesis will be shared with the above supervisors/collaborators where appropriate.

Overall word count: 18 891 (excluding tables, figures, footnotes, references and appendices)

Summary

Family caregivers are significant in the care of people with dementia, whilst the changes that occur as a result of dementia impact on both the person with dementia and family caregivers. As this caregiving is set within a significant social relationship, it is important to explore the factors within this social context that may both support and compromise the caregiver. The current thesis sought to explore the impact of social emotions and social identities within this caregiving context.

Chapter 1 presents a systematic review of the literature exploring the self-conscious emotions of guilt and shame within the dementia family caregiver. It explores the emotional and cognitive experience of caring for a person with dementia within the context of this social relationship. Broadly, findings highlight the negative influence of the caregiver's self-conscious emotions, on relationships and connection to the Person with Dementia (PwD) and others. Methodological limitations are outlined with regards the clarity of the results whilst clinical implications and suggestions for future research are discussed.

Chapter 2 presents a qualitative research investigation exploring the construction of identity in dementia caregivers' contributions to an online support forum. The analysis focuses on identities apparent within talk about the dementia caregiving relationship. This analysis reveals the construction of two prominent and interacting identities, that of 'fragile self' and 'fighter self.' The potential clinical implications of identity exploration for caregivers are discussed.

Chapter 3 offers a reflective account of my experience of the research process in relation to my own social relationships.

Chapter One: Literature Review

‘The Self-Conscious Emotions of Guilt and Shame in Family Caregivers of People with Dementia: A Systematic Review of the Literature’

In preparation for submission to *Clinical Psychology Review* (see Appendix A for Author Instructions)

Tables are presented within the thesis chapter to aid overall clarity; these will be moved to the end of the paper prior to journal submission as per the author guidelines.

Overall chapter word count (excluding tables, figures and references): 7 819

1.1. Abstract

Objective: The self-conscious emotions of guilt and shame are emotions which arise within the context of an interpersonal relationship such as the dementia caregiving relationship. This systematic review aims to critically evaluate empirical literature that has sought to investigate these self-conscious emotions, within the context of the dementia family caregiving relationship.

Methods: The databases PsycINFO (EBSCO), MedLine (EBSCO), Cinahl (EBSCO), Web of Knowledge and Scopus were searched. Citation and reference list searches of key articles were carried out. Fifteen articles met the inclusion criteria.

Results: The evidence relating to dementia caregivers' experience of guilt and shame translated into the following main themes: Relationship context; protective factors and vulnerabilities; impact of behavioural symptoms and expression; negative feelings towards the person with dementia (PwD); progression of illness and sense of responsibility.

Conclusions: Broadly, findings highlight the deleterious influence of self-conscious emotions on relationships and connection to the PwD and others. This suggests the need to enhance assessment, formulation and intervention in relation to caregiver's experience of guilt and/or shame. However, firstly it is important to unravel the conceptual confusion of these emotions in order to facilitate this clinical process, and to mobilise service resources accurately and effectively.

Keywords: Guilt; shame; dementia; Alzheimer's; caregiver

1.2. Introduction

1.2.1. Background

Population statistics in the United Kingdom continue to reflect a growing aging population (ONS, 2012). As the population gets older, the impact and challenge of age-related conditions such as dementia becomes greater. Dementia is progressive in nature and is marked by loss of cognitive function in a wide range of areas. This disruption has a significant impact on social and occupational functioning (WHO, 2012). Current figures estimate there to be 800,000 people living with dementia in the UK, and statistical projections suggest this figure will rise to over 1,000,000 people by 2021 (Alzheimer's Society, 2013). Parallel consequences of which include a growing dementia caregiving population and an increased demand for supportive and diagnostic services and resources.

1.2.2. Caregiving and dementia

New or different behaviours relating to sleep, eating, agitation or aggression may present as dementia progresses (Little & Doherty, 2008), evoking strong, and often difficult emotions for caregivers. Indeed, it is the increase in behavioural symptoms that is often cited as significant regarding decisions made over long-term care (Sury, Burns & Brodaty, 2013), impact on relationship quality (de Vugt, 2003), and the experience of burden (Coen, Swanwick, O'Boyle & Coakley, 1997). Changes in personality and fluctuating levels of insight accompany progressive behavioural changes. This all occurs within the context

of a 'living loss' from a significant other (Bruce & Schultz, 2001) and introduces complicated and specific challenges to the interpersonal relationship between the caregiver and the person with dementia (PwD).

1.2.3. Dementia and social relationships

1.2.3.1. The care dyad

The expression of social emotions may become compromised as dementia progresses. Indeed, with gradual disturbance to communication, the PwD's ability to communicate with the caregiver is interrupted. In the context of a long-term dyadic relationship, this interruption and disturbance to the rules of reciprocity (Eloniemi-Sulkava et al., 2002) is likely to be difficult for the caregiver, particularly in the context of a significant attachment relationship (Bowlby, 1969; Bowlby, 1984).

The level of interpersonal disconnect will differ as a result of disease severity, dementia diagnosis and individual difference, including factors such as relationship quality, access to support networks and resilience (Ablitt, Jones & Muers, 2009; Donaldson & Burns, 1999) and knowledge of dementia (Graham, Ballard & Sham, 1997). However, changes to the PwD empathic abilities (Hsieh, Irish, Daveson, Hodges & Piguet, 2013), disruption to emotional recognition (McCade, 2013), and emotional perception (Phillips, 2010) have significance within a relational context and specifically within interpersonal relationships such as the dementia care dyad.

1.2.3.2. The dementia caregiver

Social relationships are important regarding both psychological (Baumeister & Leary, 1995) and physiological functioning (Norman, Hawkley, Cole, Bernston & Cacioppo, 2012). Indeed, the impact of disruption to the social relationship between the dementia caregiver and the PwD is likely to be experienced as highly stressful, unsettling and may stimulate a physiological response in the caregiver (Gilbert, 2009, 2010) as exploration of immune and cognitive function suggests (Cacioppo, Hawkley, Norman, & Bernston, 2011; Norman et al., 2012).

The propensity for this changing social relationship to evoke a psychological reaction in the caregiver is presented in research (Pinquart & Sörensen, 2003; Simpson & Acton, 2013; Wright, 1991). Indeed, decisions over long-term care, negative emotions towards the PwD and negotiation and conflict between other roles and responsibilities (Zarit & Edwards, 2008) have the potential to introduce moral and ethical dilemmas that are emotionally demanding for the caregiver. Interestingly, the potential activation and maintenance of moral or self-conscious emotions (Tangney & Dearing, 2002), has received little empirical attention. This is despite wide recognition and acknowledgment by clinical practitioners that the self-conscious emotions of guilt and shame are commonly expressed and experienced by dementia caregivers.

1.2.4. Self-conscious emotions

Guilt and shame are defined as self-conscious emotions alongside embarrassment and pride (Tangney & Dearing, 2002; Tracy, Robins & Tangney, 2007). They require an internal evaluation of the self against standards, rules and goals absorbed through culturalisation in society. As these feelings are associated with negative evaluation in reference to what is perceived as good or right, these emotions are often referred to as ‘moral emotions’ (Tangney & Dearing, 2002). One’s actions, thoughts and feelings are evaluated against this social barometer, and if an aspect of the self is perceived to have failed, then self-conscious emotions emerge (Lewis, 1971). These emotions require a concept of the self (Tracy, Robins & Tangney, 2007) whilst developmentally this is not thought to emerge until self recognition occurs at around 18 months (Taylor, 2005).

A more concrete definition of these emotions is offered by Tangney and Dearing (2002). Guilt is suggested to relate to a response to specific behaviours (*I did that nasty thing*) and can motivate social reparation with the other. Shame is related to a global attribution to the whole self (*I did that nasty thing*) and typically results in disruption to social relationships with others, leading to social withdrawal and disconnection (Tangney & Dearing, 2002). The greatest clarity of definition originates from a broadly cognitive behavioural view of guilt and shame, whilst this limitation has informed an aspect of the current exploration concerning how guilt and shame are conceptualised.

The theoretical context to the study of self-conscious emotions has involved contribution from psychoanalytic psychology (Schore, 1991; Kohut, 1966, Freud, 1961d, Klein, 1937), alongside cognitive (Beck, Emery & Greenberg, 1985), social (Hoffman, 1981), and evolutionary schools (Gilbert, 1989). The enduring theme is that self-conscious emotions are informed by our social connections with others and they support our ability to manage and protect social relationships, to maintain order and hierarchy, and to reinforce attachments and bonds.

1.2.5. Guilt, shame and clinical symptoms

The greatest evidence for a link between self-conscious emotions and behavioural or clinical symptomology relates to guilt and shame. These self-conscious emotions have been linked to depression (Kim, Thibodeau & Jorgensen, 2011; Tangney, Wagner & Gramzow, 1992), suicide (Mokros, 1995; Hendin & Haas, 1991), anxiety (Allan, Gilbert & Goss, 1994), eating disorders (Goss & Allan, 2009; Frank, 1991) and psychosis (Turner, Bernard, Birchwood, Jackson & Jones, 2012). Furthermore, guilt is also cited in DSM V (American Psychiatric Association, 2013) in relation to the diagnosis of major depressive disorder whilst the absence or presence of ‘guilty feelings’ is explored within the Beck Depression Inventory (Beck, 1978).

1.2.6. Guilt, shame and caregiving

Guilt and shame have been found to be significant to an experience of burden in adult daughters caring for aging mothers (Gonyea, Paris & de Saxe Zerden, 2008), to family caregivers of those at end-of-life stages (Harst de, Andershed, Roxberg & Brunt, 2013; Andershed, 2006), in family caregivers of a relative with severe and enduring mental illness (Wasserman, de Mamani & Suro, 2012; Boye, Bentsen & Malt, 2002; Natale & Barron, 1994), and in the context of cancer care (Spillers, Wellisch, Kim, Matthews & Baker, 2008).

The literature on guilt and shame in general (Tangney & Dearing, 2002) and relating to dementia caregiving (Martin et al., 2006; Losada et al., 2010) reveals the concepts of guilt and shame are poorly and inconsistently defined and operationalised. Determining the most accurate ways of capturing and assessing experiences of guilt and shame in this caregiver population is critically important as a result of the specific nature of some of the challenges that present, links to clinical symptoms and the potential insight into avenues of intervention.

1.2.7. Rationale

Guilt and shame are significant emotions observed in caregivers of people with dementia and it is important to understand these emotions in relation to a profile of caregiver distress. Within research there appears to be a wide range of definitions and conceptualisations of guilt and shame resulting in the application of research methodologies that are as equally disparate. In view of this

confusion, an attempt will be made to consider the strengths and limitations of the measurement of these self-conscious emotions. Furthermore, implications will be presented in relation to both research and clinical fields.

1.2.8. Aim of the current review

To critically evaluate the empirical literature investigating the self-conscious emotions of guilt and shame within the context of the dementia family caregiving relationship.

1.2.9. Research question

‘What is currently known about the self-conscious emotions of guilt and shame in the context of dementia family caregiving?’

1.3. Method

1.3.1. Search Strategy

Search terms were informed by the research question.

Table 1.1. Search terms based on the review question

Concept	1. Dementia	2. Self-conscious emotions	3. Caregiver
Search term	Dementia	Guilt Shame	Caregiver
Additional variation	Alzheimer Alzheimer's		Care Caregiv* Family

*Note. Terms taken from Concepts 1, 2 and 3 were combined using the Boolean operator “and”. * represents truncation in order to capture variation used in the terminology.*

The number of synonyms was limited, which is in part reflective of the specific nature of the terms but also helped to offer a more robust, clear and replicable search strategy particularly in the case of the self-conscious emotions.

1.3.2. Data Sources

Initially the Cochrane database and the Centre for Reviews and Disseminations (DARE) were searched confirming that there were no existing reviews of guilt and shame in the context of dementia caregiving.

A systematic literature search was conducted in the databases, PsycINFO (EBSCO), MedLine (EBSCO), Cinahl (EBSCO), Web of Knowledge and

Scopus. These databases were chosen in order to reflect the psychological and psychiatric nature of the key concepts under exploration. Studies registered in the PsychINFO (EBSCO), Medline (EBSCO) Cinahl (EBSCO), and SCOPUS databases were searched within the title, abstract and keywords. The Web of Knowledge database was searched within the title and topic.

1.3.3. Selection Criteria

While the searches were not restricted to a particular time frame, the literature search was conducted on 22nd January 2014 consequently studies published after this date were not considered. In order to assess the relevance of articles, inclusion and exclusion criteria were applied.

1.3.3.1. Inclusion criteria

Studies were included if: (i) published in a peer reviewed journal; (ii) the paper was written in English; (iii) the sample included current family caregivers for a person with dementia (any type); (iv) the PwD had a diagnosis of dementia which was not alongside any other major cognitive or physical illnesses or diagnoses; (v) the self-conscious emotions of guilt and shame were identified or explored as part of the aims of the study, as dependent variable(s), or as a key theme identified within research findings (in qualitative studies).

1.3.3.2. Exclusion criteria

Studies were excluded if: (i) the paper was a review, editorial, commentary, book chapter, conference proceeding, response, letter, discussion piece or legal paper; (ii) a case study was used; (iii) the study looked at attitudes, perceptions or hypothetical scenarios of caregiving rather than exploring actual experience, (iv) it was an intervention study; (v) the sample of caregivers had been screened and selected on the basis of a particular characteristic i.e. high grief.

1.3.4. Manual search

A manual search was then performed on the papers identified following application of the criteria above. The reference lists and citation lists of all papers identified within these searches were reviewed for relevant published research.

1.3.5. Search results

The study selection process is shown as a flow diagram in Figure 1.1. After the study selection process was completed 15 studies remained.

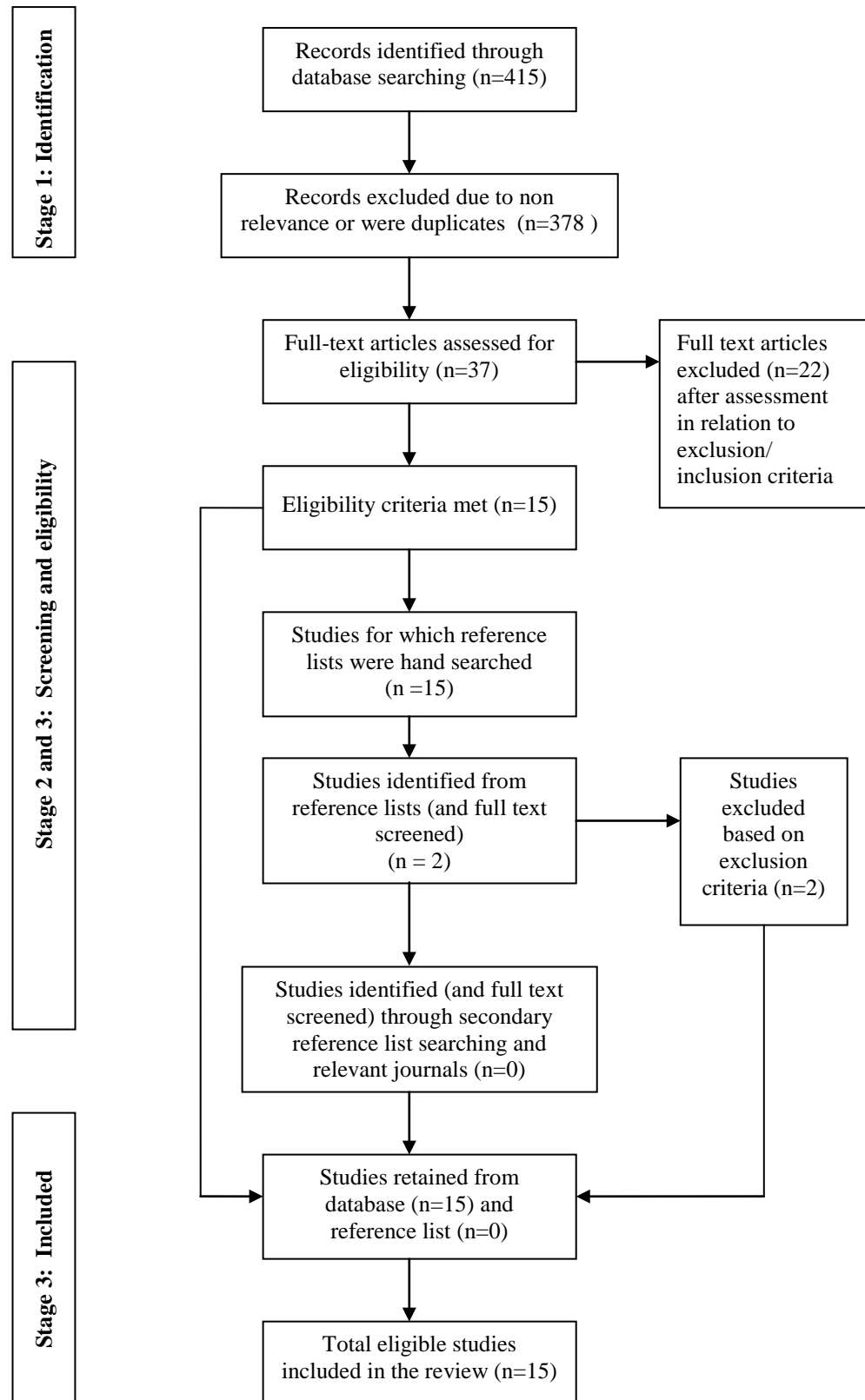


Figure 1.1. Flow diagram based on PRISMA presenting the study selection process (Liberati, 2009).

1.3.6. Assessment of quality

In order to assess the quality of research included in this review a quality assessment framework was used. There are few frameworks that offer a clear and comprehensive guide to assessing the quality of both quantitative and qualitative literature (as identified in the current review) and no standard exists.

The framework by Caldwell and colleagues (2005) was found to be the most applicable to the papers comprising the current review (see Appendix D).

Adaptations were made to this framework (see Appendix E) as the intention was to streamline the framework in order to enhance clarity, specificity and consistency. These adaptations were informed by consideration of other quality assessment work (Glynn, 2006; Sale & Brazil, 2004).

In order to maximise consistency in the current quality assessment more guidance was offered (see Appendix F & G). The research was considered against each quality criterion, and rated as: 0 criterion were not met; 1 criterion partially met; or 2 criterion met. The total number of ratings was then calculated (out of 32 for qualitative and out of 34 for quantitative). The mean for qualitative research was 20.86 with a range of 9-29, while the mean for quantitative research was 28.75 with a range of 22-33.

1.3.6.1 Reliability of quality ratings

In order to establish whether the quality assessment of the articles was consistent, two articles were rated independently by another reviewer. There was some

difference across ratings however this was never more than a one point discrepancy on any criteria and overall the total quality rating only differed by a maximum of 2 points.

1.3.6.2. Summary of quality assessment

All papers were assessed regarding their quality (see Appendix H & I) and no studies were excluded on the basis of poor quality. The quality review process supported the assessment of the strength of evidence. This was particularly useful in relation to the methodological quality and potential bias in the reviewed research. This was taken into account when the studies were critically appraised.

There is a difference in quality ratings when considering the quality scores for quantitative research against those of qualitative research. Overall, quantitative research scored more highly in relation to quality than qualitative research.

There is some challenge to comparing both research methodologies in view of their different epistemologies and there is potential that such differences are a consequent artefact of this. Indeed, this challenge may be indicative of the paucity of quality frameworks that explore both research methodologies and the differences in quality ratings found within the quality assessment conducted within the current study.

1.3.7. Data extraction and synthesis

There is well-developed literature on the synthesis of quantitative evidence but a paucity of research relating to qualitative synthesis (Dixon-Woods, Booth, & Sutton, 2007). However, the techniques involved in synthesising qualitative evidence do allow for a wider spectrum of evidence to be considered and have the advantage of allowing the structure of the review to develop, rather than being imposed. The current review identified both qualitative and quantitative research papers. It was important to adopt a method that would integrate both types of evidence generated from the research question. The decision was made to adopt a qualitative approach to synthesis.

Following the identification of relevant studies each paper was reviewed closely in relation to the findings offered to the research question of the current review. A thematic analysis was conducted in order to provide a framework to the exposition of common patterns within the findings (Braun & Clarke, 2006). This enabled the identification of predominant or recurring themes and formed the basis for the synthesis and presentation of the research findings (Aveyard, 2007; Dixon-Woods, Agarwal, Jones, Young & Sutton, 2005).

1.3.8. General study characteristics

The characteristics of the studies are summarised in Table 1.2.

Table 1.2. Summary of study characteristics

Authors, Country, Aim of Study	Design	Sampling Method	Sample Size	Sample Characteristics	Measures	Data Collection	Statistical Analysis	Findings	Quality Score
Boykin & Winland-Brown (1995). USA. To understand the experience of being a caregiver for a loved one with Alzheimer's disease	Cross-sectional	Purposive	5 caregivers	Recruited from: Alzheimer's day care centre. Gender: Males 2. Females 3. Mean age: Spouses were in their 70s, whilst daughters and daughter-in-law were both between 46 and 55. Relationship to care recipient: 3 spouses, 1 daughter, 1 daughter-in-law Length of time caring: Mean 8.4 years. Range- 6 months to 6 years. Ethnicity: No information Dementia diagnoses: AD Dementia severity: No information	None	Semi-structured interviews (asked one broad question)	Phenomenological Study, Colaizzi (1978)	Four main themes: 1) The progression of the disease results in feelings of frustration and sacrifice of self 2) Caregivers find courage to continue through sharing and living in the moment 3) Altered perceptions of reality and time result in the need for constant supervision 4) Caregivers struggle with guilt as they try to be authentically "with" and to retain respect and dignity for loved ones.	9/32
Conde-Sala, Garre-Olmo, Turró-Garriga, Vilalta-Franch & López-Pousa (2010). Spain. To identify and compare factors associated with caregiver burden in spouses and adult-children caring for a person with Alzheimer's disease	Cross-sectional	Purposive	251 caregiver dyads	Recruited from: Memory and Dementia Assessment unit Gender: Males 34.0%. Females 66.0% Mean age: Spouses- 73.66. Range 56-87) adult-child- 49.39. Range 28-65. Relationship to care recipient: 112 spouses and 139 adult-child Length of time caring: No information Ethnicity: No information Dementia diagnoses: AD Dementia severity: minimal, mild moderate and severe.	Caregiver Burden Interview- CBI (Zarit et al, 1986)	Measures completed.	Quantitative-multivariate linear regression analysis	Greater burden among adult-child caregivers who also report higher guilt.	32/34
Forbes, Bern-Klug & Gessert (2000). USA. To explore both cognitive and emotional aspects of decision	Cross-sectional	Purposive	28 caregivers	Recruited from: Four nursing homes Gender: Males 23.4%. Females 76.6 % Mean age: 66 years. Range 41-85. Relationship to care recipient: 10 daughters, 4 wives, 4 husbands, 3 daughter- in- law, 2 sons, 2 sisters, 1 nephew, 1 sister-in-law, 1 grandson	None	Focus groups	Content analysis	Decisions regarding the PwD were found to be made whilst struggling with overwhelming burden and guilt.	27/32

making regarding end of life treatments for those with moderate to severe dementia				Length of time caring: No information Ethnicity: No information Dementia diagnoses: Not specified Dementia severity: Moderately severe to severe.					
Garity (2006). USA. To identify how family caregivers experienced their caregiving role following placement of PWD in a residential home	Cross-sectional	Purposive	18 caregivers	Recruited from: AD support groups offered in three nursing homes. Gender: Males 22%. Females 78%. Mean age: 53.3 years. Relationship to care recipient: Daughters- 72%. Daughters-in-law- 6%. Sons 17%. Friends- 5%. (N.B. States that there were two sets of sisters and one husband and wife set although these participant's do not appear in the studies description of sample characteristics) Length of time caring: No information Ethnicity: No information Dementia diagnoses: AD Dementia severity: No information	None	Semi-structured interviews	Content analysis	Family caregivers positive interactions with others including the PwD, other residents, family and friends and staff, and support groups positively impacted on coping. However, negative interactions with the above led to a negative impact on coping. Factors identified as impacting on coping included: role disruption, guilt over placement and uncertainty about the future.	23/32
Gessert, Forbes, & Bern-Klug (2001). USA. To examine families end-of-life decision making regarding relatives with dementia and interactions with health care professionals	Cross-sectional	Purposive	28 caregivers	Recruitment from: Four nursing homes. Gender: No information Mean age: No information Relationship to care recipient: No information Length of time caring: No information Ethnicity: No information Dementia diagnoses: No information Dementia severity: Moderately severe to very severe	None	Focus groups	Content analysis	Emotional burden of stress and guilt was found to be identified by most caregivers within their roles as decision makers.	21/32
Høgenes, Melin-Johansson, Norbergh & Danielson. (2013). Sweden. To explore the	Cross-sectional	Purposive	11 caregivers	Recruitment from: Nursing homes and by social workers Gender: Males 3. Females 8. Mean age: 73 years Relationship to care recipient: Wives- 8, husbands -3. Length of time caring: No information	None	Semi-structured interviews	Content analysis	Feelings of shame and guilt were identified as present both before and after nursing home placement. The spouses suggested they wanted to protect the PwD from making a fool of	27/32

existential life situations of spouses caring for a partner with dementia both before and after nursing home placement				Ethnicity: No information Dementia diagnoses: Information is not specific but diagnoses are listed to include AD, vascular dementia and frontal temporal lobe dementia Dementia severity: No information				themselves and this led to social isolation. Guilt appeared to be associated with failure.	
Karlin, Bell & Noah (2001). USA. To examine the long term consequences of caring for PwD	Longitudinal (recruited from earlier follow up study)	Purposive	51 caregivers	Recruited from: Earlier quantitative study. Gender: Males 43.1%. Females 56.9%. Mean age: 67.3 years Relationship to care recipient: Adult-child- 37.2%; spouse- 54.9%; sibling- 3.9%; grand-child - 2%; distant relative 2% Length of time caring: Mean 8.4 years. Range 1.3-22. Ethnicity: 48 Caucasian, 1 African-American, 2 Hispanic. Dementia diagnoses: AD Dementia severity: No information	None	Semi-structured interviews	Thematic analysis	There were 7 themes identified: role issues and role reversal, problems and burden of being a caregiver, support sources and resources, support group issues, protection, nursing home placement, and guilt, research awareness and participation and additional contributions as a caregiver.	10/32
Losada, Marquez-Gonzalez, & Penacoba (2010). Spain. To develop a measure that will assess guilt in the context of dementia caregivers	Cross-sectional	Purposive	288 caregivers	Recruited from: Social and Health Care Centers. Gender: Males 20.8%. Females 79.2%. Mean age: 59.63 years Relationship to care recipient: Spouse- 37.2%; adult-child- 57.6%; other relative- 5.2% Length of time caring: No information Ethnicity: No information Dementia diagnoses: AD- 58.4%, other dementia, 41.6% Dementia severity: No information	Zarit Burden Interview (Zarit et al 1980) The revised memory and behavioural problems checklist, (Teri et al 1992) Barthel Index (Mahoney and Barthel, 1965) to explore functional status Leisure time satisfaction measure, (Stevens et al 2004) The Psychosocial Support Questionnaire (PSQ; Reig et al 1991) The Tension Anxiety subscale from the profile of mood states	Semi-structured interviews	Principal components analysis	22 items from the measure were retained. The factors were named: guilt about wrong doing by the care recipient, guilt about not rising to the occasion as caregivers, guilt about self care, guilt about neglecting other relatives and guilt about negative feelings towards other people. Reliability was acceptable and significant associations were found to CGQ and ZBI guilt factors.	32/34

					(POMS, McNair et al 1971) Center for Epidemiological Studies-Depression Scale (CEDS-D; Radloff, 1977)				
Martin, Gilbert, McEwan, & Irons (2006). England. To examine the relation of entrapment, guilt and shame to depression in the dementia caregiving context.	Cross-sectional	Purposive	70 caregivers	Recruited from: Alzheimer's database Gender: 17 Males. 53 Females. Mean age: No information Relationship to care recipient: No information Length of time caring: 15 care for up to 15 years; 12 for 4-6 years; 11 for 6-8 years, eight for over 8 years. Ethnicity: No information Dementia diagnoses: No information Dementia severity: No information	Center for Epidemiological Studies-Depression Scale (CEDS-D; Radloff, 1977) Clifton Assessment Procedures for the Elderly (CAPE) and Behaviour Rating Scale (BRS, Pattie and Gilleard, 1979) Carers Entrapment Scale The Caring Shame and Guilt Scale.	Measures completed.	Pearson's product moment correlation (to explore relationship) Multiple regression (to explore statistically significant associations)	Entrapment was highly related to depression. Shame was also significantly related to depression, entrapment and guilt. Guilt was not found to be associated with depression or entrapment.	26/34
Navab, Negarandeh, Peyrovi & Navab (2012). Iran. To understand the experiences of family caregivers caring for PWD in Iran	Cross-sectional	Purposive	10 caregivers	Recruited from: Iran Alzheimer's Association. Gender: 2 Males. 8 Females. Mean age: 48.7 range- 25-67 years Relationship to care recipient: 6 daughters; 4 spouses (2 wives; 2 husbands) Length of time caring: Range 1-11 years Ethnicity: No information Dementia diagnoses: AD Dementia severity: No information	None	Semi-structured interviews	Qualitative study using Hermeneutic Phenomenology, Van Manen (2001)	Two themes were identified of: 'feeling of shame due to the unusual behaviour and speech of the patients' and 'fear of judgements made by others'	29/32
Parks & Pilisuk (1991). USA. The psychological costs of providing care for a parent with Alzheimer's	Cross-sectional	Snow-balling	176 caregivers	Recruited from: A University medical centres Alzheimer's disease clinic. Gender: 51 Males. 125 Females. Mean age: No information Relationship to care recipient: All adult children to a parent with Alzheimer's disease	Hopkins Symptoms Checklist-90 (Derogatis, 1982) Measured by a 7 item locus of control measure. The Burden Interview	Structured interview	Principal factor analysis to explore coping styles Multiple regression	The analysis identified four categories of burden. Two of which were psychological: guilt and resentment, and two were identified to work load and environmental factors: being overwhelmed	22/34

				Length of time caring: No information Ethnicity: Almost entirely white No information Dementia diagnoses: AD Dementia severity: No information	(Zarit, Gatz & Zarit, 1981; Zarit et al 1980) The provisions of social support scale, (Turner, Frankel & Levin, 1983)			and embarrassed. 4 coping styles were revealed: objectifying, fantasy, withdrawal, internalising,	
Romero-Moreno, Losada, Marquez, Laidlaw, Fernández-Fernández, Nogales-González & López (2013). Spain. To analyse the moderator role of guilt in the caregiving relationship in relation to frequency of leisure activity and depressive symptoms and to explore whether guilt is influenced by kinship	Cross-sectional	Purposive	351 caregivers	Recruitment from: Social and health care centres and advertisement in print media, internet or television. Gender: Males- 21.37%. Females- 78.63%. Mean age: 60.19 years Relationship to care recipient: 207 daughters; 37 sons; 69 wives; 38 husbands. Length of time caring: Mean of 11.77 hours daily. Ethnicity: No information Dementia diagnoses: 58.4% caring for a relative with Alzheimer's, 41.6% for a relative with other dementia. Dementia severity: Information not clear	Caregiver Guilt Questionnaire (Losada et al, 2010) The Revised Memory and Behaviours Problems Checklist (Teri et al 1992) Barthel Index, (Mahoney & Barthel, 1965) Adaptation of the Leisure Time Satisfaction Assessment, (Stevens et al 2004) The Center for Epidemiological Studies-Depression (CES-D) scale (Radloff, 1977)	Face-to-face interviews.	Quantitative-Hierarchical regression analysis	A moderator role for guilt was found but only for daughters. In this group, engaging in less leisure activity, and showing higher levels of guilt was found to be associated with more depressive symptoms, whereas those with lower guilt showed lower depressive symptoms.	33/34
Roach, Laidlaw, Gillanders & Quinn (2013). UK. To test the psychometric properties of the Caregiver Guilt Questionnaire in British dementia caregivers	Cross-sectional	Purposive	221 caregivers	Recruited from: A larger project exploring outcome measures for dementia caregivers. Gender: 34.4% Males. 65.6% Females. Mean age: 68.6 Relationship to care recipient: Spouse 80.5%; adult-child 17.3%. Length of time caring: 4.4 years. Ethnicity: No information Dementia diagnoses: Alzheimer's disease- 51.4% Other dementia- 33.5% Dementia severity: No information	Caregiver Guilt Questionnaire (Losada et al., 2010) Zarit Burden Inventory Guilt factor, (ZBI Zarit et al 1980) Center for Epidemiological Studies Depression, (CES-D, Radloff, 1977)	Measures completed.	Principal axis factoring	The 5 factor structure of guilt found by Losada et al. (2010) was replicated in a British sample of dementia caregivers. Factors were: 'guilt about doing wrong,' 'guilt about failing to meet the challenges of caregiving' 'guilt about self-care' 'guilt about neglecting other relatives' and 'guilt about having negative feelings towards other people.'	30/34

Rudd, Viney & Preston (1999). Australia. To examine the grief responses of spousal caregivers who cared for their partners who had dementia at home with those in ongoing nursing home care	Cross-sectional	Purposive	60 caregivers	Recruited from: No information Gender: 30 Males. 30 Females. Age: 51-60, N= 27; 61-70, N=100; 71-80, N=187; >80, N= 86. Relationship to care recipient: 30 wives and 30 husbands. All spouses. Length of time caring: No information Ethnicity/Nationality: 76.5% Australian; 18.25% Anglo other; 6.6% European Dementia diagnoses: Not specified Dementia severity: No information	The Cognitive Anxiety Scale, (Viney & Westbrook, 1976) Hostility in Scale (Gottschalk & Gleser, 1969) Guilt Anxiety Scale (Gottschalk & Gleser, 1969) Affects balance scale (Derogatis, 1975)	Interview	Content analysis MANOVA	Nursing home caregivers expressed significantly more guilt and sadness. Home caregivers expressed significantly more anger. Home caregiving wives were found to be the most angry and expressed significantly higher levels of anxiety, sadness and anger than husbands.	26/34
Werner, Mittelman, Goldstein & Heinik (2011). Israel. To explore whether family stigma is a predictor of caregiver burden in the context of Alzheimer's disease	Cross-sectional	Convenience/ snowball	185 caregivers.	Recruited from: Support groups organised by the Israeli Alzheimer's Association (IAA) Gender: Males 25.4%. Females 74.6%. Mean age: 52.7 years Relationship to care recipient: All adult- child caregivers Length of time caring: mean- 5.4 years Ethnicity: no information but place of birth included: Israel- 75.5%; Europe/America-17.3%; Asia/Africa- 5.9% and Other 1.1% Dementia diagnoses: AD Dementia severity: No information	Zarit Burden Interview Short Form (ZBI-SF; Bedard et al 2001) FS-ADS Problematic behaviour scale, Pearlin et al 1990	Structured interviews	Spearman's Correlation (to assess relationship) Multiple regression (to explore statistically significant associations)	The caregiver variables of 'shame' and 'decreased involvement in caregiving' were found to be major contributing factors to the experience of burden.	31/34

1.4. Results

The evidence broadly translated into the following themes: Relationship context; protective factors and vulnerabilities; impact of behavioural symptoms and behavioural expression; negative feelings towards the person with dementia; progression of illness and sense of responsibility. The research findings in relation to each of these themes will now be presented, alongside critical appraisal of the evidence.

1.4.1. Relationship context

1.4.1.1. Relationship to person with dementia

A number of quantitative studies explored the significance of the type of relationship the caregiver holds to the PwD in relation to guilt feelings. This was explored in four of the eight quantitative studies. Conde-Sala, Garre-Olmo, Turró-Garriga, Vilalta-Franch and López-Pousa (2010) reported that adult-child caregivers who experienced more feelings of guilt also experienced greater burden when compared with spouses. The most significant differences between the two groups were apparent in relation to guilt, above other factors such as social burden and psychological distress. Furthermore, guilt was found to be stronger in relation to adult-child caregivers who did not live with the PwD when compared with those caregivers who did.

However, it is important to note that Conde-Sala et al. (2010) used the Zarit Burden Interview (ZBI) to explore guilt feelings whilst there are a number of limitations in using this measure. For example, guilt has not been identified as a factor following factor analysis in other research using the ZBI (Whitlatch, Zarit & von Eye, 1991; Knight, Fox & Chou, 2000; Bédard et al., 2001; O'Rourke & Tuokko, 2003). Therefore this may not be appropriate in exploring guilt in this population. Furthermore, the measure offers judgement of any guilt feelings as an aspect of caregiver burden, yet this may not be the case for all caregivers (Schwartz, Meisenhelder, Yusheng & Reed, 2003; Andrén & Elstahl, 2005).

The interaction between the type of relationship the caregiver holds to the PwD and an experience of guilt was explored in other research using The Caregiver Guilt Questionnaire (CGQ). Similarly to Conde-Sala et al. (2010) Losada et al. (2010), Roach et al. (2013), and Romero-Moreno et al. (2013) identified that adult-child caregivers report higher levels of guilt than spouses. In further exploration, Romero-Moreno et al. (2013) noted daughters reported higher levels of total guilt, compared with wives, and more guilt relating to a perception of wrong doing and negative feelings towards the PwD. Only in relation to the daughter caregiver sample, was guilt found to have a moderating effect between leisure activities and depressive symptoms.¹

The CGQ was originally developed by Losada et al. (2010) whilst the cross-cultural validity of the measure was investigated by Roach et al. (2013) with encouraging results. Overall, robust investigation of the validity of this measure

¹ In relation to: 'guilt total score'; 'guilt about wrong doing'; 'guilt about failing to meet the challenges of care giving' and 'guilt about self care'.

has been undertaken and favourable results are offered concerning the application of this measure to a dementia caregiver sample.

1.4.1.2. Wider social relationships

In other research, Rudd, Viney and Preston (1999) identified that husbands in particular experienced guilt as a result of the development of closer relationships with others. However, the evidence presented here was generated from a poorly specified and unclear research methodology. This includes a weak rationale, confusion over qualitative and quantitative methods of analysis, and concerns over the validity of the measures used². In particular there appears to be a confounding of guilt and shame in this measure and a lack of clear explanation of the concept of guilt. These factors challenge the strength of the evidence offered from this study.

1.4.1.3 Gender difference

The possible impact of gender concerning an experience of guilt was explored in three quantitative studies (Roach, et al., 2013; Losada, et al., 2010 & Romero-Moreno et al., 2013). Roach et al. (2013) and Losada et al. (2010) reported that females were more likely to experience guilt than male caregivers. Losada et al. (2010) suggested this was particularly apparent within the specific aspects of ‘*guilt about neglecting other relatives*’ and ‘*guilt about having negative feelings towards other people*’.

² The Guilt Anxiety Scale (Gottschalk & Gleser, 1969) was used.

In Losada et al.'s (2010) research, females accounted for 79.2% of the sample population. This is important to note as the factors of guilt identified above may have been more commonly endorsed by females as a result of potential influence from latent factors. As females were over-represented in this sample the overall findings may be limited in terms of their generalisability to male caregivers.

Roach, et al. (2013) did not offer a breakdown in relation to gender which would have been interesting due to the greater number of males in the overall sample of this study (females accounted for only 65.6%).

Romero-Moreno et al.'s (2013) finding relating to daughters high levels of global guilt adds further strength to the suggestion that being a female adult caregiver may introduce increased vulnerability to an experience of guilt.

1.4.2. Protective factors and vulnerabilities

1.4.2.1. Coping

A number of the studies explored aspects of coping in relation to an experience of guilt in dementia caregiving (Losada et al., 2010; Roach et al., 2013; Romero-Moreno et al., 2013; Parks & Pilisuk, 1999). Parks and Pilisuk (1999) explored the role of locus of control, finding a low sense of mastery in women predicted guilt. However, it is worth noting that this study presented with a low score following quality assessment, particularly due to concern over the generalisability of the findings relating to poor demographic detail of the sample and the caregiving sample being drawn from a University medical clinic. In

addition the study is limited as the ZBI was used to explore guilt feelings (see page 36).

One of the factors identified within the CGQ was '*guilt about self-care*' (Losada et al., 2010; Roach et al., 2013; Romero-Moreno et al., 2013). Losada et al. (2010) suggested that this factor related to guilt as a result of the caregiver looking after themselves through engaging in activities other than caring for the PwD. Importantly, Losada et al. (2010) reported that caregivers who engaged in more leisure activity scored lower in relation to '*guilt about self-care*.'³ Furthermore, Romero-Moreno et al. (2013) reported for those caregivers with high guilt about self-care, more depressive symptoms were linked to lower frequency of leisure activities whilst higher frequency of leisure activities was linked to less depressive symptoms.

1.4.2.2. Clinical presentation of caregiver

A number of quantitative studies explored the potential links between the self-conscious emotions of guilt and/or shame and the clinical presentation of the caregiver (Martin et al., 2006; Losada et al., 2010; Romero et al., 2013 & Roach et al., 2013). Depressive symptoms and anxiety were the only aspects of clinical presentation explored in the research comprising the current review. Martin et al. (2006) found that aspects of shame were significantly related to depression, entrapment and guilt. However, aspects of guilt were not found to be associated with depression or entrapment. This initially appears surprising considering the

³ Also in relation to '*guilt about doing wrong by the care recipient*'

research links made in clinical populations between guilt and depression (Kim, Thibodeau & Jorgensen, 2011). The potentially self-destructive nature of shame has been proposed to result in more deleterious consequences to an individual, whilst guilt may offer the potential for greater opportunity for social reparation (Tangney & Dearing, 2002). On this basis, the relation of guilt and shame to the presentation of depressive symptomology is likely to be different. However, the measurement of the self-conscious emotions in this study requires further consideration.

Martin et al. (2006) used '*The Caring Shame and Guilt questionnaire*' - a measure that attempts to explore both guilt and shame. This measure was designed for the study and whilst the researchers do offer some discussion of how they have conceptualised guilt and shame, there is inadequate rationale in relation to how the items comprising the measure were developed and how they relate to a dementia caregiving population unlike the CGQ explored earlier (Losada et al., 2010). Overall '*The Caring Shame and Guilt questionnaire*' lacks clarity and definition, with minimal psychometric data. Furthermore, it is important to note that the measurement of both guilt and shame within one measure offers potential for confounding the two emotions. This is a particular risk owing to the lack of clarity in definition and conceptualisation of guilt and shame.

In other quantitative research exploring the potential links between the self-conscious emotions and the clinical presentation of the caregiver Losada et al. (2010) found strong associations between guilt, depression and anxiety.

Specifically, caregivers with higher scores on the CGQ also scored higher on measures exploring negative appraisal of behavioural problems, depression and anxiety. In further research using the CGQ, Roach et al. (2013) identified a clinical cut-off whereby scores (above 22) are associated with a clinical level of depressive symptoms (as indicated on the CES-D). Whilst this suggests that guilt may be associated with depressive symptoms, it is not possible to make causal inferences on this basis. Furthermore, the reliability of this cut-off needs further exploration as the level of specificity is low (61.5%).

Other research by Romero et al. (2013) reported that for those caregiving daughters who were identified to engage in low levels of leisure activities, higher levels of guilt were associated with higher levels of depressive symptoms. A reduction in depressive symptomology as a result of an increase in leisure activities was only apparent for those with high levels of guilt. Such findings indicate the possible benefits of behavioural activation (i.e. increase in meaningful activity) for such daughter caregivers.

1.4.2.3. Links to other self-conscious emotions

One study identified potential overlap between guilt and other self-conscious emotions. Parks and Pilisuk (1999) found that male caregivers who reported a high sense of embarrassment also reported high guilt feelings.

1.4.3. Impact of behavioural symptoms and behavioural expression

1.4.3.1. Impact of shame on relationships

A number of studies suggest the experience of shame may impact on relationships, both within wider social relationships as well as within the care dyad. This appeared most evident when studies reported on the caregiver's response to the PwD behaviours. Behavioural symptoms are more likely in moderate to severe stages of dementia. Consequently the caregiver may be more vulnerable to an experience of shame along with associated consequences when caring for a PwD at this stage.

Navab, Negarandeh, Peyrovi and Navab (2013) reported the challenging behaviours of the PwD (such as '*nasty behaviour and speech*') led to feelings of shame when exposed publicly as apparent in both more intimate family settings and the wider community. In order to manage this experience of shame caregivers resorted to social isolation. The transferability of these specific findings must be approached with caution as the study was conducted in Iran. The findings have however been echoed in other qualitative investigation in other cultures as indicated below.

Høgnæs, Melin-Johansson, Norbergh and Danielson (2013) reported caregivers to describe feelings of guilt and shame as a result of the PwD engaging in behaviours such as shoplifting. What reportedly followed was the caregiver's withdrawal from activities that presented more opportunity for the PwD to

engage in these behaviours and further withdrawal from activities with families and friends ‘*because it was easier.*’ Høgnæs et al. (2013) also found that it was difficult for caregivers to talk about feelings of shame as this tended to invite feelings of guilt. This research study was conducted on a Swedish population. Issues of transferability are important to consider as with Navab et al. (2013).

In quantitative exploration, Werner et al. (2011) found the caregiver stigma variables⁴ of shame and decreased involvement in caregiving were major contributing factors to burden. If this is considered alongside the qualitative findings outlined above, there is indication that an experience of shame has the potential to impact significantly on the wellbeing of both the caregiver and the relationship within the care dyad. A conceptualisation of shame is absent in this study, as shame is explored as a variable within the broader conceptualisation of family stigma. This has implications regarding the specificity of the exploration of shame, when compared to the direct exploration of shame within other research (Martin et al., 2006).

1.4.3.2. Impact of guilt on relationships

The impact of the experience of guilt regarding social relationships was also identified within research findings. In a qualitative study, Boykin and Winland-Brown (1995) highlighted the potential for a positive outcome to the experience of guilt. Guilt appeared to facilitate greater consideration of the PwD, leading to an enhanced commitment to them (Boykin & Winland-Brown, 1995). This

⁴ Other dimensions included: ‘Lay persons stigma’ and ‘Structural stigma’

finding appears to reflect the views of key theorists in the study of guilt and shame suggesting that guilt has the propensity to repair and protect relations with significant others (Tangney & Dearing, 2002).

Quantitative exploration offered by Losada et al. (2010) reported caregivers who experience guilt were also found to report low scores in relation to social support. This finding suggests that an experience of guilt may impact on a caregiver's ability to engage with social support. In addition, the study reported all but one of the guilt factors were found to be significantly associated with negative appraisals made about behavioural problems and a greater frequency of behavioural problems. These findings suggest the potential for behavioural symptoms, most likely in moderate to severe stages of dementia, to expose vulnerability to an experience of guilt.

1.4.4. Negative feelings towards the person with dementia

Guilt following recognition of negative feelings or actions towards the PwD by the caregiver was identified in some research findings. Boykin and Winland-Brown (1995) identified guilt feelings experienced by the caregiver following their responding angrily to the PwD or treating them like a child. In further qualitative enquiry, Karlin, Bell and Noah (2001) reported similar findings in relation to an acknowledged negativity towards the PwD. These studies must be considered carefully regarding the clarity and strength of evidence offered. Areas of weakness relate to the methodological design, definition of major concepts and transferability of findings.

Quantitative research by Losada et al. (2010) and Roach et al. (2013) identified one of five factors within the CGQ to relate to guilt in relation to the experience of negative emotions. As reported earlier, Losada et al. (2010) identified female caregivers, and adult-child caregivers caring for a parent, were more likely to experience ‘*guilt about having negative feelings towards other people*’⁵. In further research using the CGQ Romero-Moreno et al. (2013) reported that the factor ‘*guilt about negative feelings towards others*’ did not moderate the relationship between frequency of leisure activities and depressive symptoms for daughters, sons, wives or husbands.

1.4.5. Progression of illness

1.4.5.1. Guilt over long-term care

Engaging with decisions over the long-term care of the PwD was identified as significant regarding the self-conscious emotions elicited (Forbes, Bern-Klug & Gessert, 2000; Garity, 2006; Høgnæs et al., 2013). Forbes, Bern-Klug and Gessert (2000) reported decisions over long-term care were made within the context of ‘*overwhelming burden and undying guilt*’. Guilt was not found to resolve following the PwD commencement of a long-term care placement. Furthermore, Garity (2006) suggested that guilt reduced the caregiver’s ability to cope with decisions over long-term care. It is important to note that there is a lack of clarity regarding the methodological approach taken by Garity (2006),

⁵ Above males, spouses and other relatives

thereby questioning the robustness of this evidence. Furthermore, this was a retrospective study, raising issues of reliability within the data obtained. In more general comment, the studies outlined above (Forbes, Bern-Klug & Gessert, 2000; Garity, 2006; Høgnæs et al., 2013) offer evidence gained from samples of family caregivers with relatives in long-term care. These findings may not be transferable to family caregivers at home.

Høgnæs et al. (2013) identified that feelings of shame were present both before and after nursing home placement. Feelings of guilt and shame in spousal caregivers appeared to be generated as a result of perceived abandonment of the PwD. Participants also identified feelings of guilt and freedom which were associated with placing their spouse in a residential home. It appeared a sense of freedom connected to a '*shadow of guilt or bad conscience*'.

This is a useful study due to the exploration of caregiver experiences, both before and after the commencement of a long-term care placement in addition to exploration of both guilt and shame. However, as with Forbes et al. (2000) and Garity (2006) the study relies on participants remembering their experiences prior to placement, which raises issues of reliability. Furthermore, it is important to note that two of the spouse's relatives with dementia had died whilst their cases were still included in the sample. Their experiences of guilt are likely to be different and thus issues regarding the homogeneity of the sample are raised.

1.4.5.2. Feelings of failure in relation to an experience of guilt

This theme appeared most evident when caregivers were engaged with decisions over long-term care. A number of qualitative studies identified an experience of perceived failure by the caregiver in their role and associated guilt when decisions over long-term care were reflected on, and action taken (Gessert et al., 2001; Høgnæs, et al., 2013). Guilt feelings were not found to resolve as a result of a long-term care placement commencing (Forbes et al., 2000; Karlin et al., 2001).

In quantitative research, the factors ‘*guilt about doing wrong by the care recipient*’ and ‘*guilt about failing to meet the challenges of caregiving,*’ were identified within the five main factors in the CGQ (Losada et al., 2010). Both appear to relate to a punitive and critical approach to self from the caregiver.

1.4.5.3. Cognitive dissonance

The process of amending social and moral values and related cognitions as a result of perceived dissonance appears to have been alluded to in three studies (Garity, 2006; Karlin et al., 2001; Rudd et al., 1999). Garity (2006) reported that guilt identified in relation to nursing-home placement, was reduced following recognition of the PwD’s need for 24 hour care. Whilst Karlin, et al. (2001) suggested a dissatisfaction regarding long-term care was discussed as potentially motivated by an experience of guilt.

Rudd et al. (1999) reported that if the caregiver role appeared to have contributed to physical health problems, then the caregiver did not feel guilty over the placement into a nursing home. This was most apparent when the caregiver had been offered permission by a figure of perceived authority such as a doctor (Rudd et al., 1999). These examples illustrate attempts to rationalise, justify, and ease the discomfort of actions taken that are incongruent with personal constructs. Rudd, et al. (1999) reported caregivers guilt feelings appeared related to a conflict in personal constructs between placing the PwD in residential care and a view that they did *'not see themselves as the type of person who would do such a thing'*.

1.4.6. Sense of responsibility

1.4.6.1. Responsibility for others

Both qualitative (Gessert et al., 2001; Forbes et al., 2000) and quantitative (Losada et al., 2010; Romero-Moreno et al., 2013) research studies explored the experience of perceived responsibility for the care of the PwD. Some studies suggest the difficulty for caregivers in splitting themselves between the PwD and other responsibilities (Gessert et al., 2000) introduces significant guilt. Forbes et al. (2000) highlighted specific tension between the responsibility felt for young children in addition to the PwD as generating significant guilt feelings.

It is important to note that the findings of the qualitative studies above offer a component of a wider research exploration of end-of-life care in dementia. It is

unfortunate that neither paper appears to offer substantial critique or discussion of the research limitations, and consequently may be more vulnerable to researcher bias.

The qualitative findings are supported within quantitative research, Losada et al. (2010) and Roach et al. (2013) identified a factor within the CGQ to be '*guilt about neglecting other relatives*'. Romero-Moreno et al. (2013) and Losada et al. (2010) using the CGQ, reported females as scoring higher in relation to '*guilt about neglecting other relatives*' than males. Furthermore, Losada et al. (2010) suggested that adult-child caregivers were more likely to report guilt in relation to this factor, than spouses or other relatives.

1.4.6.2. 'Breaking promises'

A feeling of betrayal was a significant experience in relation to feelings of guilt over long-term care. This was described as a feeling of '*breaking promises*' and going against the express wishes of the PwD made years before (Garity, 2006; Gessert et al., 2001; Karlin et al., 2001). The dissonance between these moral values alongside the related obligations made to the PwD appeared hard to assimilate and to compound a sense of guilt.

1.5. Discussion

The aim of the current review was to critically evaluate empirical literature that has sought to investigate the self-conscious emotions of guilt and shame within the context of the dementia family caregiving relationship. The findings will now be discussed and tentative conclusions offered regarding consideration of the current evidence and opportunity for further enquiry.

1.5.1. Discussion of findings

1.5.1.1. Vulnerable groups

The current review suggested that adult-child caregivers were particularly vulnerable to an experience of guilt above other family members such as spouses. With regards to gender females were highlighted as a group more vulnerable to an experience of guilt. Interestingly, this experience appears in part to relate to female concerns about ‘others,’ with this social preoccupation facilitating an experience of guilt. This concern to protect and facilitate relations may link to a sense of perceived responsibility, which is felt most strongly by female dementia caregivers.

1.5.1.2. Clinical presentation

Findings in relation to guilt, shame and clinical symptomology were inconsistent and as a result inconclusive. This is surprising considering the links made

between these self-conscious emotions and depression (Kim, Thibodeau & Jorgensen, 2011). Ruminatory processes particularly linked to depression and a downward spiral of cognition do have some resonance across, and within, some of the themes identified in the current review such as feelings of failure in relation to an experience of guilt (see page 47). In view of the link between guilt and some diagnostic processes (American Psychiatric Association, 2013; Beck, 1978), this area requires further exploration.

1.5.1.3. Impact of guilt and shame

When considering the impact of guilt and shame concerning the connection between the caregiver and the PwD, shame was found to be particularly detrimental. Shame was associated with the caregiver seeking to socially isolate themselves resulting in the isolation of the care dyad (Navab, 2013; Hognes, 2013; Werner, 2011). However, these conclusions remain tentative as they are generated from a limited evidence base. The potential negative impact of guilt was also discussed in relation to decreased engagement in social support which has the propensity to impact on both the caregiver and the PwD (Losada et al., 2010). Interestingly, there were some findings indicating that guilt may have the potential to improve the connection to the PwD (Boykin & Winland-Brown, 1995). This resonates with the wider literature on the potentially reparative nature of guilt (Tangney & Dearing, 2002).

Guilt and shame appeared most apparent in relation to factors associated with illness progression such as decisions over long-term care (Forbes, Bern-Klug &

Gessert, 2000; Gessert et al., 2001; Garity, 2006; Høgnnes et al., 2013) and behavioural symptoms of the PwD (Navab et al., 2013; Høgnnes et al., 2013; Werner et al., 2011). These external factors were discussed in relation to the influence of internal consequences that enhanced an experience of caregiver guilt such as feelings of betrayal (Garity, 2006; Gessert, Forbes & Bern-Klug, 2000; Karlin et al., 2001). Internal processes that defended or managed against guilt feelings related to the repair that was prompted following an experience of cognitive dissonance (Garity, 2006; Karlin, Bell & Noah, 2001; Rudd et al., 1999). This internal process of repair was not facilitated through social interaction such as with the PwD. Indeed, disturbance to reciprocal social communication in the latter stages of dementia obstructs the potential for social reparation with the PwD. It is likely that the more an individual can self manage difficult feelings and conflicts and adapt to this social change, the more protection is offered concerning the impact of these self-conscious emotions. However, it also appears there is a balance to be struck between the avoidance of these emotions, whether through physical or emotional means and the need to experience these emotions in order to prompt relevant action.

1.5.1.4. Conceptualisation

The fusion of the two emotions in research investigation has led to a lack of clarity about which emotion is being measured or explored. However, this may also suggest that there is a relationship between guilt and shame that requires further exploration. Indeed, Tangney and Dearing (2002) refer to maladaptive guilt as a term used to reflect the potential fusion or overlap between guilt and

shame. However, it is also important to recognise that findings within the current review suggest that the consequences of both guilt and shame appear to be qualitatively different promoting the need for research endeavours that attempt to clarify these concepts.

There appeared to be more research exploring the self-conscious emotion of guilt within the current review. This may in part be owing to the very nature of shame as a hidden emotion prompting social withdrawal. This may also be due to the exploration of guilt for researchers, and the disclosure of guilt for caregivers being more acceptable than the emotion of shame in relation to a relative with dementia.

1.5.1.5. Methodology Issues

In view of the conceptual confusion apparent in this research area it is important to consider how best to clarify the current evidence and enhance the robustness of future research in this area. It appears that further qualitative research may be best placed to explore the conceptualisation of guilt and shame in more detail. This would allow a broadening out of research enquiry to include exploration of the complexities and nuances in the experience of guilt and shame for dementia caregivers. Due to weaknesses in clarity of some qualitative methodologies, more explicit methodological process would be beneficial, whilst qualitative research questions with a more specific focus on guilt and shame would offer more depth to research investigation.

The quality of quantitative research was also varied. One weakness found was in relation to measures used to investigate the self-conscious emotions, which appeared to relate to how the emotions had been conceptualised. However, the CGQ offers the most promise regarding the assessment of the emotion of guilt (Losada et al., 2010). Furthermore, quantitative research was most adept at revealing further information regarding relationships to other factors and in relation to the screening and monitoring of self-conscious emotions. This line of research enquiry needs to be maintained.

It was notable that there was a very limited amount of data offered in relation to sample characteristics such as length of time caregivers had been caring, ethnicity and severity of dementia. This is important to comment on as the variance within these factors could result in implications to the heterogeneity of the sample considered in this review.

1.5.2. Research implications

The current review suggests that whilst tentative conclusions can be drawn from the developing literature, there are a number of areas in relation to the experience of self-conscious emotions in the dementia caregiver that require further research attention. These include:

- The theoretical and conceptual understanding of guilt and shame
- The potential interaction between guilt and shame
- The impact of disturbance to social reciprocity concerning an experience of guilt and/or shame

- Protective factors that might mediate against the negative impact of guilt and/or shame
- The links between guilt and/or shame in relation to clinical symptoms
- The link between the stage of dementia and an experience of guilt and/or shame
- The potential for guilt to be socially reparative in the dementia caregiving relationship

1.5.3. Clinical implications

1.5.3.1. Clinical assessment

The current review indicates that clinical practitioners are more likely to hear expressions of guilt rather than shame from caregivers. However, whilst this may be the case, practitioners should be encouraged to attend to the whole experience of the caregiver as guilt may harbour feelings of shame that may be more difficult for caregivers to express and for clinicians to identify. Furthermore, normalising the experience of guilt and shame within the caregiving relationship may support caregivers to talk about these feelings.

1.5.3.2. Clinical intervention

Within one-to-one therapeutic interaction with caregivers, it is important to offer a non-judgemental space that offers the potential to recognise, contain and talk

about feelings of guilt and shame. Indeed, it is only once feelings are disclosed, that possible interventions can be considered.

The findings of the current review lend support to clinical interventions aimed at enhancing self-compassion and raising awareness of self-criticism, such as compassionate mind training and mindfulness (Gilbert & Proctor, 2006; Gilbert & Irons, 2005; Kabat-Zinn, 1994). Furthermore, such interventions may be of particular relevance considering the ruminatory processes linked to guilt and in view of the link to depression (Segal, 2002).

Shame and guilt appeared to be associated with social withdrawal, which may have deleterious effects for both the caregiver and the PwD. The value of connecting caregivers to socially available, inclusive and supportive networks and groups is highlighted, in order to maximise the potentially positive effects of the value of social connectedness.

The positive impact of an increase in leisure activity was also highlighted in the current review (Romero-Moreno et al., 2013). Engaging caregivers in positive, meaningful activity may offer an accessible coping strategy that protects against depressive symptoms. Importantly, the benefits of behavioural activation may be greater for those caregivers who are experiencing higher levels of guilt in relation to their own self care.

1.5.4. Limitations of the current review

The current review does present with a number of limitations. In relation to study selection, the criteria used in the review may have excluded relevant literature as the review only focused on peer-reviewed studies published in English which may have resulted in a publication bias. Fifteen articles were found that met the inclusion criteria for this review, however, some of the papers offered substantially more material to the research question than others. This appeared to be linked to the variety of methodologies employed in the papers that met inclusion criteria.

When the research question was applied to the literature a mixture of both qualitative and quantitative research was found. Owing to the developing but limited research in this area, it was important that the review was query-led rather than methodology-led. As a result, the review set out to critique both qualitative and quantitative research. Studies employing a quantitative methodology were explicit about their explorations of guilt and/or shame, whilst qualitative aims were not able to direct the investigation so explicitly and findings typically were drawn out of broader aims. Therefore, whilst it is hoped that all relevant qualitative studies were captured for review, the implicit nature of such investigation made this more challenging.

There were a number of limitations relating to the sample population of the current review. Females appeared to be over-represented in the sample when considering females have only a slightly greater representation in the national

population (ONS, 2011). This is important to consider in relation to the generalisability of findings, particularly when considering the applicability to male caregivers. This may be indicative of a natural trend for dementia family caregivers to be female, or it may be influenced by other differences between these two groups.

Interestingly there is suggestion that females are more likely to develop dementia which would suggest that males would be more likely to be caregivers (Alzheimer's Society 2014). However, for reasons that need further empirical consideration male caregivers commonly represent a smaller proportion of dementia caregiver research samples. Whether male caregivers represent an unreported sample of caregivers who do not access services and do not come forward to engage in research is yet to be fully explored.

There was only one study conducted within the UK (Roach et al., 2013) which has implications regarding the applicability of the findings of the literature review to the UK caregiving population. It is important to note that in cross cultural exploration of the utility of one measure of guilt across both Spanish (Losada et al., 2010) and UK (Roach et al., 2013) dementia caregivers that the same factors were identified across both caregiving populations. This suggests potential cultural commonality in the experience of these emotions. This needs further research attention, especially in view of the theoretical literature that suggests guilt and shame are set within a social and cultural context (Lewis, 1971).

The samples were mainly recruited from care services or environments such as nursing homes, support services and memory clinics. Therefore, the experiences of those caregivers who are not accessing services is not captured in this review. This, alongside the cross-sectional nature of the majority of studies, invites caution regarding the extrapolation of findings to all dementia family caregivers. In addition, only 4 out of the 15 articles reported findings in relation to shame. As the majority of exploration was around the experience of guilt, drawing conclusions in relation to shame is problematic.

1.5.5. Conclusions

The study of guilt and shame involved both qualitative and quantitative methods, with much difference seen within these approaches. The range of methods used appears to relate in part to the differing concepts of guilt and shame underlying the studies. Overall, the studies comprising the current review all present evidence that guilt and/or shame are experienced by the caregiver in the context of dementia. These emotions were found to mostly result in negative consequences for dementia caregivers both emotionally and socially. The importance of identifying these emotions in caregivers is significant as the potentially negative consequences of guilt and shame are translated and constructed in the context of this caregiving relationship, having real and practical consequences to both the caregiver and the PwD.

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Chapter Two: Empirical Paper

‘The Construction of Identity in Dementia Caregivers’ Contributions to an Online Support Forum: A Discourse Analysis’

In preparation for submission to the *British Journal of Psychology* (See
Appendix B for Author Instructions)

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2.1. Abstract

Objective: Minimal research attention has focused on the identity of dementia caregivers whilst even less research has adopted a discursive approach to considering dementia caregiver identity. The current study aims to bridge these gaps through exploring identity construction in everyday talk from dementia caregivers.

Methods: A discourse analysis was performed using data from an online support forum for dementia caregivers. This analysis explored how identities are constructed and what identity is being used to achieve in interaction.

Results: This analysis revealed the construction of two prominent and interacting identities, that of ‘fragile self’ and ‘fighter self.’ These identities were used to appeal for sympathy (‘fragile self’), call for action against perceived injustice (‘fighter self’) and present and protect moral character. The fragile self was seen to orient to the fighter self position through interaction.

Conclusions: Discourse analysis of dementia caregivers’ talk reveals the varied use of dementia caregiver’s identities in interaction. This allows the potential for dementia caregivers to orient to alternative identities which may have benefits for all engaged in such supportive exchanges.

Keywords: Dementia; Alzheimer’s; caregiver; identity; discourse analysis

2.2. Introduction

The changes that occur as a result of dementia impact not just on the person with dementia (PwD), but also on significant others such as the caregiving spouse (Conde-Sala, Garre-Olmo, Turro-Garriga, Vilalta-Franch & Lopez-Pousa, 2010). Changes to the rules of reciprocity (Laursen & Hartup, 2002) within such social relationships result in both perceived and real shifts to the PwD's social identity. A parallel process operates as caregivers' self identity shifts in response to changing social rules and roles within the caregiving relationship (Andershed, 2007; Karner & Bobbitt-Zeher, 2005). As this process of readjustment is socially constructed, social interaction itself is likely to provide an authentic window into how such social action is performed. The current paper begins with a broad overview of the literature in relation to dementia caregiving and identity, and then presents the discursive work in this area. This is followed by an analysis of how caregivers contributions to an online dementia support forum construct and manage identity. Furthermore, what these identities are used to achieve in interaction will also be explored.

2.2.1. Dementia

Dementia is a progressive, debilitating and irreversible condition that is characterised by significant loss of cognitive ability impacting on a wide range of functioning (WHO, 2012). The impact of this cognitive loss alongside the statistical projections of the expanding aging population (ONS, 2012) suggests an increasing demand is likely to be placed on the resources of caregivers. The

vast majority of these caregivers will be family or friends of the PwD, (Knapp et al., 2007). The importance of considering the needs of both the PwD and their caregivers alongside an ethos of quality of care was highlighted in the first national dementia strategy (Department of Health, 2009).

2.2.2. Dementia care

The person centred approach to dementia care encourages an attunement to the social identity of the PwD promoting the concept of ‘personhood’ as central (Kitwood, 1997). Personhood is defined as ‘*A standing or status that is bestowed on one human being, by others, in the context of relationship and social being*’ (Kitwood, 1997, p. 8). This highlights the importance of considering social identity as co-constructed through interaction with others.

The importance of social relationships draws attention to the interaction between the PwD and significant others such as the caregiving spouse. As dementia advances, increasing disturbance to the rules of reciprocity (Laursen & Hartup, 2002) places challenges on the caregiving relationship. Furthermore, the challenges of dementia losses relating to role adjustment are significant and invite a process of adaptation and a reconstruction of aspects of social identity (Montgomery & Williams, 2001). Research has suggested that changes in the caregiving spouse’s identity impact on how these caregivers identify themselves within the marital relationship (Hayes, 2009).

Considering the social arena in which these processes of adjustment take place it is important to consider how research methodologies may be adopted that are sympathetic to this dynamic interaction through exploring the use of language in publicly constructing and manifesting the social self. Discursive psychology is thus presented as a well placed approach to the investigation of identity construction in interaction (Carbaugh, 1996; Gergen, 1994).

2.2.3. Discursive psychology

In sympathy with Kitwood's (1997) person centered approach to dementia care, discursive theorists have challenged the traditional biomedical and cognitive approaches to dementia and dementia care (Adams, 1998). Discursive psychology adopts the view that rather than language being reflective of an internal world, that it is critical in the construction of a social world (Potter & Wetherell, 1989; Potter, 1996).

Social interaction is active, dynamic and adaptive and is not employed merely to describe or reflect on the world (i.e. cognition) but '*...it is the site where meanings are created and changed*' (Taylor, 2001, p. 6). Discursive psychologists are interested in this process and focus research attention on this interaction as the setting where social action becomes live such as through processes relating to the construction and management of identity, accountability and authenticity. This approach allows '*discourse to be treated as a social practice which can be studied as a real world phenomenon rather than a theoretical abstraction,*' (Edwards & Potter, 1992, p. 15).

Identity construction as a '*real world phenomenon*' (Edwards & Potter, 1992, p. 15) has been explored using discourse analysis within the field of mental health in relation to difficulties such as eating disorders (Giles, 2006), depression (Drew, 1999), schizophrenia (Meehan, 2008), and autism (Brownlow, 2006). Although limited discursive research within the area of dementia and dementia care has been undertaken, some research of particular relevance will now be considered.

2.2.4. Discourse and society

Social interaction has been explored within wider frameworks and social structures in connection to dementia, such as relating to media discourse (Peel, 2014) and the judicial system (Harding, 2012). Peel (2014) revealed in discursive analysis of media discourse a framing of dementia through the use of catastrophic metaphors, whilst informal caregivers did not use such hyperbole in their talk and did not focus on discussion of responsibility or accountability for the condition. In exploration of legal discourse Harding (2012) revealed discussion around mental capacity may be operating to restrict the PwD and thus impact on the ability to support and maintain personhood. The benefits of a discursive approach to interaction become apparent in relation to dementia and dementia care through revealing the social action relevant stakeholders engage in through discourse.

Dementia caregivers' talk about care services has also received discursive research attention (Peel & Harding, 2013). Three main themes emerged of 'services as a maze,' 'services as overly limited-beyond our remit' and 'the battle and fighting discourse' used by caregivers. In acknowledging the significance of the wider social context of discourse relating to dementia, it is of particular importance to consider the micro level social context of interaction. The most frequent, influential and enduring social interactions within this context occur within the care dyad between the PwD and the dementia caregiver. Consequently, the social action performed within this dynamic is of particular interest.

2.2.5. Discourse and identity

The person centred approach to dementia appears to have encouraged a burgeoning research literature around the identity of the PwD (see Cadell & Clare, 2009 for a review). Discursive research reveals the identity of the PwD as preserved but in need of maintenance through social interaction (Small, 1998; Sabat & Harrè, 1992). In exploration of a dementia support group Henman (2014) suggested that the PwD appeared to use identity to draw out a sense of strength and agency. Additionally Henman (2014) commented that PwD were able to 'position and reposition' themselves with the support of others (p. 11).

Rather less attention has been paid to the identity of the dementia caregiver (Hayes, 2009) with even less research in this area adopting a discursive approach. Forbat (2003) offered a discursive analysis of the interactions within a

care dyad drawn from research interview. Analysis revealed gender roles, family positioning, power differentials and moral dimensions such as that of 'good carer' and 'bad carer' to be drawn upon. This analysis focused attention on identity constructions and the discussion of relationship tensions in reference to the past relationship. Such work highlights the potential for a discursive approach to reveal the construction of problems whilst offering potential to explore the function of such constructions within the dementia caregiving relationship.

A discursive framework to dementia and dementia care has been outlined by Adams (1998). Adams (1998) offered discussion of the construction of care, highlighting the importance of considering the position of family members and the PwD within an exploration of discourse. Later empirical work exploring identity in dementia reveals how language is used by formal and informal caregivers in research interviews to construct identities relating to both the PwD and caregivers (Adams, 2000). Identities such as 'informant,' 'worrier' and 'concerned carer' were mobilised by a family caregiver in interaction with a community psychiatric nurse (CPN) to perform a range of accomplishments such as to justify criticism of care and to support credibility in action.

Discursive research in this area has not been limited to the study of dementia caregiver speech. Other discursive research has been conducted by Kirsi (2000) on the written stories of caregiving husbands. This revealed that different identities were adopted by husbands such as 'observer', 'reporter', 'responsible caregiver', 'independent actor', 'victim' and 'drifter.' The performance of

identity revealed tensions between different roles such as that of ‘carer’ and ‘man.’ Such research reveals the construction of identity as prominent in caregiver discourse whilst there is considerable variation in the use of identity as a result of context. This research was undertaken on a Finnish sample of caregiving husbands with a data corpus generated for research purposes, the challenges of which will be explored later.

Although there has been some discursive research undertaken in this area, overall there is a lack of consistently robust discursive research exploring the construction of identity in dementia caregiving spouses. Hepburn et al. (2002) explored the emergence of different identities in dementia caregivers, however whilst a component of analysis focuses on the discourse of the caregivers, the way in which language is constructed within this discourse has not received explicit attention. This interpretative approach to exploration adheres to the cognitivist view that language conveys underlying cognitions and beliefs and is a reflection of the internal world of the speaker rather than focusing on the action within verbal exchanges. Overall, there has been no extensive research work undertaken using a discourse analysis of the talk of dementia caregivers natural and everyday interaction.

The use of subject positions and the harnessing of dominant discourses reveal active and powerful social action implicit within language use in the construction of identity (Edley, 2001). This research supports an understanding of identity as created within the context of interaction with another and not something that belongs to an individual (Abell & Stokoe, 2001). Indeed, such research findings

resonate with both the concerns and the opportunities in dementia care highlighted by Kitwood (1997). This, along with the research outlined above suggests a research emphasis should be placed on exploring not what identity is, but *how* it is constructed and what it accomplishes in everyday talk.

2.2.6. Rationale

Dementia prompts significant readjustment and redefinition of caregiver identity. As identity is a social co-construction occurring in response to and in connection with others, social interaction itself is likely to provide an authentic window into how such social action is performed. Whilst the identity of the caregiving spouse has received some empirical attention from discursive researchers, the data has typically been ‘researcher provoked,’ with some research lacking an explicit and robust approach to discourse analysis. The richness offered in natural and everyday talk of dementia caregivers is an authentic and privileged resource that facilitates a means of accessing everyday social interaction in order to explore the discursive construction and management of identity. Discourse analysis is sympathetic to this dynamic interaction allowing the exploration of discursive practices that publicly construct and manifest the social self.

Owing to the construction of self occurring within a social arena it was appropriate to focus on social relationships that are likely to have the greatest frequency of social interaction. Spouses to PwD are more likely to be living with the PwD and therefore more likely to have more social contact. This focus also

allows the analysis made to be more accurate to a specific dementia caregiving population.

2.2.7. *Aim*

The aim of the proposed study is to explore how spousal caregivers talk about the caring relationship and the identities that this relationship makes relevant within the context of dementia.

2.2.8. *Research question*

- i) How do dementia spousal caregivers present and manage their own identity within the context of the caring relationship with a person with dementia?
- ii) What is identity used to achieve in the interaction of dementia spousal caregivers?

2.3. Methodology

2.3.1. *Ethics*

The moderators of the ‘*Talking Point*’ forum at the Alzheimer’s Society were contacted and following submission of a research proposal (Appendix J) permission was given to conduct the research (see Appendix K). Ethical approval was also granted by Coventry University (see Appendix L). ‘*Ethics*

Guidelines for Internet-Mediated Research' produced by the British Psychological Society (2013) were adhered to. Steps were taken to protect contributor's anonymity and pseudonyms were used. When an online search was completed using examples of the extracts used in the analysis, none of the extracts were found to offer links to the Talking point forum which offered further anonymity.

Individual consent from contributors was not gained. The forum represented information published within the public domain and not requiring any membership to view. However, careful consideration was given to issues of consent and all principles outlined by the British Psychological Society (2013) were considered and adhered to.

2.3.2. *Everyday interaction*

There has been debate in the exploration of social identity around the use of 'researcher-provoked' data (Giles, 2006, p. 465). Some researchers question the need to engineer research data when it is possible to access '*real world data*' (Silverman, 2001, p. 159) and also in view of the challenges that 'researcher-provoked' data can present (see Potter & Hepburn, 2005 and Potter & Hepburn, 2012). Within the context of dementia, Perkins, Whitworth and Lesser (1998) suggest 'researcher provoked' methods may '*result in a discourse sample that is unlikely to reflect what happens between people with dementia and their caregivers on a daily basis*' (p. 35). An avenue for exploration opens concerning

accessing everyday talk of dementia caregivers in order to explore social action in everyday interaction.

2.3.3. *Online support forums*

Online interactions can be treated as conversations that host features of interaction such as the use of discursive devices. Identity can be used as a rhetorical device to construct, present and manage interactions within such settings (Horne & Wiggins, 2009; Lamerich & te Molder, 2003). Indeed, research has begun to employ a discursive approach to exploring identity within interaction on online support forums relating to eating disorders (Giles, 2006), suicide (Horne & Wiggins, 2009) depression (Lamerichs, 2003) and bipolar disorder (Vayreda & Antaki, 2009). Consequently, online contributions to a dementia support forum offer an important and relevant social communication for discourse analysis concerning how caregivers construct identity within talk about dementia.

2.3.4. *Data corpus*

The corpus of data for the current research was drawn from the Alzheimer's Society online discussion forum '*Talking Point*.' This forum is an open access forum that is available to the public with no membership necessary to view the forum. As the Alzheimer's Society host this forum and are the main national care and research charity for people with dementia and their caregivers the forum

is likely to capture contributions from a significant number of caregivers. The forum is a very active and well used resource that hosts ten sub-forums⁶.

2.3.5. Selection of data

As the research question relates to spousal caregivers' talk in the context of a dementia caregiving relationship, the sub-forum '*I have a partner with dementia*' was identified and searched for the data corpus. To ensure interaction appropriate to a discourse analysis was identified, which would facilitate the social actions under investigation; the researcher only included threads that held 10 posts or more. It was also important that the thread related to discussions of a caregiving relationship. This was achieved by scanning the threads and assessing whether they included reference to the words 'carer/care/caring/caregiver' and 'person with dementia/wife/husband/partner,' or related synonyms.

The threads for analysis were taken from a two week period in February 2014.⁷ During the time frame under analysis there were 37 threads posted. Eighteen of these threads contained 10 or more posts. One of these eighteen threads was removed from analysis as it was not focused on a caregiving relationship between a PwD and a wife/husband/partner. This meant that there were 17 threads included in the current analysis.

⁶ 'I have dementia'; 'I have a partner with dementia'; 'I care for a person with dementia'; 'Younger people with dementia and their carers'; 'Lesbian and gay people with dementia and their carers'; 'Memory concerns and seeking a diagnosis'; 'Recently diagnosed and early stages of dementia'; 'Middle-later stages of dementia'; 'End of life'; 'After dementia- Dealing with loss.'

⁷ The time frame is not specified in order to preserve anonymity.

2.3.6. Conducting the analysis

Analysis intended to explore what the caregivers were attempting to accomplish in their contributions to the forum. This focus on social action in relation to what is achieved in interaction was informed by Edwards and Potter's (1992) approach to discourse analysis that presents the Discourse Action Model. The current analysis focuses on a component of the model that relates to action orientation. This involved a focus on how identities are developed and what is achieved by the use of identity in caregivers' interaction.

Data were initially read and re read to identify action orientation that was relevant to the research question. Once identified, the identities and discursive devices within the data were evidenced using extracts from the discourse. All extracts have been quoted as presented on the discussion forum whilst usernames have been replaced with numbers. All of the extracts are taken from one thread that contains 50 postings. The posts are made at different times and on different days but the interaction between the forum users is clearly identifiable. Extract 1, 2, 3 and 6 are presented in full whilst extract 4, 5, 7 and 8 present some content from the postings specified. For full extracts please see Appendix M.

The core analysis was conducted on one thread as the identities under exploration, whilst common throughout the data set as a whole, were most clearly developed in this thread. In addition, in exploring other threads on the forum it appeared the identities apparent in the thread used in the current analysis

were significant throughout much talk between dementia caregivers on the forum.

Whilst as a methodology discourse analysis makes no direct claims regarding generalisability, what it does do is focus on the action within discourse and patterns within discourse which offers information regarding what actions may be more likely to achieve particular ends (Goodman, 2008). Furthermore, the discourse action model (Potter, 1992) used in the current analysis offers a distinct, coherent and standardised way of analysing discourse in relation to social action. Thus the current analysis of one thread can be seen to offer information regarding the performance of a particular discursive strategy, in this case the use of identity, as likely to produce the same social action within other contexts (Goodman, 2008).

2.4. Analysis

The identities of ‘fragile self’ and ‘fighter self’ are prominent discursive currencies within the data set. A focus on the interactional nature of these two identities presents three distinct stages. The first stage introduces the ‘fragile self’ who is presented as weak, vulnerable and uncertain, reflecting passivity in action. The ‘fragile self’ accomplishes a range of discursive achievements. These ultimately reflect an investment in gaining help and support from others and protecting a position of ‘good carer’ and ‘wife’. The second stage involves the presentation of the ‘fighter self’ in response to the ‘fragile self’. This identity is presented as strong, knowledgeable and robust with an active, task oriented

approach. The ‘fighter self’ ultimately challenges the ‘fragile self’ through a supportive call to action. This identity is also significant in the further preservation of the moral character⁸ of ‘fragile self.’

Finally, the third stage presents this interactional exchange as facilitating a shift in position of the original contributor. The ‘fragile self’ responds to the ‘fighter self’ by taking on the ‘fighter identity’. It is the interplay and contrast between the two identities that is of interest to the current analysis.

2.4.1. ‘Fragile self’

The first extract is taken from the first post on the online thread and illustrates the construction of the identity of the ‘fragile self.’ What is of analytic interest is *how* the ‘fragile self’ is being constructed and *what* this identity is being used to do in interaction (Horton-Salway, 2001), which here presents and protects the moral character of the contributors (Gunnarsson, Hemmingsson & Hydén, 2013; Stokoe, 2003).

⁸ The reference made to the ‘moral character’ of caregivers is best understood in reference to the following quote:

‘Social conduct and social relations are essentially accountable phenomena. They are constituted through our practices of reporting, describing and reasoning and therein lies the central role that language plays in constructing social reality. Any consideration of the accountability of social conduct brings directly into focus moral dimensions of language use:’ in the (interactional) circumstances in which we report our own or others’ conduct, our descriptions are themselves accountable phenomena through which we recognizably display an action’s (im)propriety, (in)correctness, (un)suitability, (in)appropriateness, (in)justice, (dis)honesty, and so forth. Insofar as descriptions are unavoidably incomplete and selective, they are designed for specific and local interactional purposes. Hence they may, always and irretrievably, be understood as doing moral work’ (Drew, 1998:295).

Extract 1: (Day 1 of interaction 12.23am, 1st post)

C 1 (original contributor):

1. *'Hi ive been so upset today my hubby went into respite thought he would*
2. *be in there a bit longer as i can not look after him anymore, i have*
3. *serious health problems my self and hes such a tall man to me im only 5ft*
4. *hes has already been aggressive and tried to strangle me in june when then*
5. *i had to walk out and get social workers involved and now hes doing it*
6. *again but he was like it when he was young violent and abusive but only*
7. *ever in front of my family not his. Still we got through those bad years*
8. *and every thing seemed to mellow and get better. Then this discusting*
9. *horrible disease hit us and cause its lewy body hes regessing back to*
10. *when he was young and because of my health need to adress this . So its*
11. *me thats got to leave my home and take my dog to the kennels just so they*
12. *can see if he will manage on his own with cares and things but he smokes*
13. *and falls asleep with itvin his hand meening im throwing a lot of things*
14. *away because hes burt them ie his clothes carpets and such. They*
15. *know this as they have seen it i have had a mininstroke in the last fortnight*
16. *from the stress already dont get me wrong we have been married for*
17. *50yrs this yr i still love hum and only want the best for him but cant they*
18. *see its killing me litreally...'*

C1 introduces 'my hubby' (line 1) to the narrative which illustrates affection and an intimacy in connection. However, C1 then goes on to present the behaviour of her husband as deviating from this normative role within a typical marital relationship (Abell & Stokoe, 2001). This allows the difficult disclosures of C1

within the personal narrative to be received as valid and justified and defends against an accusation of ‘uncaring’ wife (Stokoe, 2003). This moral work is also achieved elsewhere (line 2) through construction of a historically consistent and reliable caregiver identity.

C1’s physical health status (lines 2-3 and lines 10 & 15) is used to suggest that it is unreasonable and risky for C1 to continue to look after her husband and serves to neutralise the potency of the moral dilemma of withdrawing from the daily care of her husband. C1’s physical health is identified as a direct causal link to help-seeking (line 10) whilst the contrast (Atkinson, 1984) between the contributor’s physical health and her husband’s stature as ‘*such a tall man*’ (line 3) positions the contributor as physically weaker than her partner. This contrast is further developed as the contributor draws on evidence from the past, that her husband has been ‘*violent and abusive*’ (line 6) and that ‘*hes regessing back*’ (line 9). This supports the credibility of C1’s fears and draws focus to her position as weak and vulnerable.

A ‘fragile self’ identity has been assumed in the past in this marital relationship (line 6). Indeed the fragile identity appears to permeate out to the couple identity, as a fragile relationship is indicated. The weaker identity of the ‘fragile self’ appears to function in response and connection to a stronger, dominant identity. A threatened position is assumed by C1 whilst her husband is constructed in a threatening position implying a power differential which again establishes the fragile identity of C1 and suggests a fragile marital relationship.

A fragile identity is further developed (line 11) through drawing upon the social category of homelessness which is amplified through suggestion C1 is being

forced by ‘them’. This situates ‘them’ as a powerful other placing pressure on C1 leading to exposure of her ‘fragile self.’ The use of the word ‘*they*’ (lines 11, 14, 15, 17) depersonalises the ‘professional other’ and allows C1 potential to criticise the wider care system rather than blame a specific individual, thus diffusing accountability. In addition, this diffusion of responsibility protects the care professionals within the system from specific attack which allows the potential for the system to still help C1.

The ‘fragile self’ is also used in order to develop justification for criticising ‘them.’ The use of the word ‘*just*’ (line 11) undermines the request that ‘*they*’ (line 11) are making as evidently unreasonable (Goodman & Burke, 2010). This is especially unreasonable when considered in the context of the ‘fragile self’ that is developed within the narrative. This is further exemplified when ‘*they*’ (line 14) are presented to ‘*know*’ (line 15) that her husband is unlikely to manage on his own. This again undermines ‘*their*’ request and suggests that C1 is the target of a pointless and contrived exercise. This develops strong validation for criticising ‘*them*.’

Justification for this criticism is further developed in lines 15-18. An extreme case formulation (Pomerantz, 1986) is used in order to highlight the severity and urgency of C1’s case which implies ‘*they*’ (line 17) are responsible for C1’s poor physical health and her potential loss of life. This is a call for ‘*them*’ to help rather than an attack on her husband, which is more socially and morally palatable.

At the close of the extract, C1 draws heavily on her relationship to her husband and her identity as a ‘wife’ following suggestion of a problematic position in line

15. This discursive work serves to inoculate against concerns over the disclosures that she has made as potentially compromising the role of wife. This also achieves some moral work as it leaves the reader with the final message that C1 wants *'the best'* (line 17) for her husband and attempts to deflect accusations that C1 is not a 'good wife.'

A fragile identity in this context is constructed in order to justify why C1 *'can not look after'* (line 2) her husband anymore, to undermine the actions of other professionals (lines 11-15) and in order to legitimise help-seeking (lines 9-10). The 'fragile self' is harnessed to appeal for help, support and understanding whilst it also serves to deflect any potential accusations of being uncaring or unwilling to care within the social roles drawn upon, such as that of 'wife' or 'carer'.

C1's use of the 'fragile identity' can be seen to work as an invitation for emotional support. The following extracts demonstrate how this identity was responded to with sympathy.

Extract 2: (Day 1 of interaction, 12.27 am, 2nd post)

1. *'Oh dear this is an awful situation for you. I can't offer any advice at all*
2. *but please know that my thoughts are with you.'*

Extract 3: (Day 1 of interaction, 12.39 am, 3rd post)

1. *'So sorry to hear your problems. Can't offer any advice but sending big*
2. *hugs'*

These extracts highlight the accomplishment of the 'fragile identity' in gaining emotional support and a sympathetic response from others. It is the fifth posting of the thread presented below in extract 4, that begins to work up a 'fighter self' in response to the 'fragile self'.

Extract 4: (Day 1 of interaction, 01.55am, 5th post)

Contributor 2 (C2)

1. *'...No no no, this is all wrong. Can you tell us what has happened*
2. *and who specifically told you what?...'*

C2 then goes on to ask 13 questions to the original contributor about aspects of her situation and her interaction with the wider care system. This questioning is then followed by direct instruction to C1 about who to contact and how. (Please see Appendix M for full extract). C1 then goes on to say:

3. *'...I hope this is of help to you. If we can help in any other way then give*
4. *us a shout, but it would useful to have the details outlined above so we*
5. *can fully understand who is giving you all this grief.'*

This post starts to develop the possibility of C1's orientation to a different position through C2 encouraging a sense of agency and ability to act. At the beginning of this extract an emphatic statement and use of a three part list (Jefferson, 1990) implies an authoritative identity that demonstrates an awareness of the issues that C1's situation raises. This interrogation appears to function in order to develop strength in the case against 'them' (extract 1, lines 11, 14, 15,

17). This establishes a moral imperative for justified action as C1's situation is suggested to be 'wrong' (line 1). The trouble indicated through potential action by C1 (extract 1, line 2-3) is owned and worked up by C2. Through developing an argument on behalf of C1, C1 is encouraged to develop their sense of agency in this situation.

The use of the word '*us*' and '*we*' (lines 3 & 4) invites others to share the position of C2. Indeed, there appears to be a drawing together in a supportive group identity of caregiver. What follows is a number of posts that corroborate the position of C2 leading to support the authority and credibility of their position. This identity draws on the social and moral rights of C1 and in doing so encourages C1 to draw upon and develop their moral agency (Carbaugh, 1996; Gunnarsson, Hemmingsson & Hydén, 2013; Stokoe, 2003).

Extract 5:⁹ (Day 1 of interaction, examples of discourse from 6th-11th post)
(04.38am, 6th post)¹⁰

1. *'WOW C2, you are amazing'*

(5.04 am, 7th post)

2. *'I also think C2 was spot on 😊'*

(09.38am, 8th post)

3. *'Lots of good advice...'*

(09.53am, 9th post)

4. *'You have received good advice...I do hope that you*

5. are not forced out of your home. Surely you can't be if your name is on

⁹ This extract is made up of post 6-11 but are line numbered as one extract. For full extract see Appendix M.

¹⁰ All the extracts explored so far cover a period of 12 hours following the initial posting.

6. *the rent book.... Please fight for you and your dog. You shouldn't have to*
7. *be treated like this.'*

(10.58am, 10th post)

8. *'...Please take C2's advise, she is usually spot on...'*

(11.53am, 11th post)

9. *'I'm lost for words. C2's post is spot on. I do hope you get things sorted*
10. *out for yourself. x'*

Extract 5 reflects a consensus and corroboration (Clouder et al., 2011) that develops stable ground for the 'fighter identity' to emerge whilst the persuasive position of C2 achieves discursive work in encouraging the potential reorientation of C1's position. The statement in Post 9 '*please fight*' (line 6) is particularly important in helping to develop a 'fighter identity.

2.4.2. 'Fighter self'

The 'fighter self' emerges as a strong and resilient identity that presents a robust sense of agency able to engage with action. This identity is in stark contrast to the 'fragile self.' However, the presence of the two identities within the same discourse serves to amplify the qualities and purpose of the other. Specifically, the implication in discourse of C1 as passive draws an authoritative response from C2 whilst this dichotomy is what establishes grounds for shifting position. The analysis in relation to 'fighter self' will now be discussed.

Extract 6 below, reflects the ‘fighter identity’ that has been developed and validated by other members on the forum. It is in response to a new posting by the original contributor C1 (12th post). In this post C1’s thanks are expressed for the comments offered by contributors whilst she indicates needing to know where she stands. This is set within further narrative construction of the ‘fragile self’ (see Appendix M for full extract).

Extract 6: (Day 2 of interaction after 2 days of no posting, 13th post, 3 days after C1’s initial post)

Contributor 3 (C 3)

1. *‘(C1), it is your home. Your husband must be removed and assessed.*
2. *You and your darling dog friend do not need to go anywhere.*
3. *You must enlist the support of an agency to help you, Alzheimer's Society,*
4. *Age UK, Carers UK, your M.P.*
5. *...please do NOT give up and move into a place that means your dog has*
6. *to be re-homed while 'they' assess your husband.*
7. *They must take him out of the situation where he is threatening you and*
8. *assess him. It's nonsense for them to suggest that it must be done within*
9. *his home. His aggression and violence means he has violated HIS*
10. *tenancy. Please don't agree to this, you have the support of the law on*
11. *your side.’*

In this extract, C3 suggests the location of the problem to be ‘*your husband.*’

The words ‘*removed*’ and ‘*assessed,*’ (line 1) suggest an objectification of C1’s husband and develops a distance between husband and wife. The distancing

from the PwD gives space for the introduction of a ‘fighter’ narrative. The initial statement (line 1) sets up the portioning of responsibility away from C1 which is developed further as the narrative continues.

This statement (line 1) serves to offer greater physical and emotional security as C3 reminds C1 that this is her home, which implies she is deserving of rights in this context. In addition, the language used implies a clinical approach to the problem, suggesting her husband must be ‘*removed*’ (line 1). This again develops a sense of distance but also suggests involvement from professional others that again portions responsibility elsewhere i.e. away from C1.

C3 draws upon the use of ‘*they*’ (line 6 & 7) which reflects the language of the ‘fragile self’ (extract 1, lines 11, 14, 15 & 17) and validates the assertion that criticism towards nameless professionals and consequently a wider care system is justified. This positioning of care professionals as a ‘generalised other’ (Holdsworth & Morgan, 2007) suggests a diffusion of responsibility that attempts to preserve C1’s moral character as care professionals are implicated as inadequate.

The use of the word ‘*must*’ evokes a sense of necessity for action which supports a bolstering and encouragement of a sense of agency in dialogue with a ‘fragile self’. This auxiliary verb is used frequently within this extract to indicate a need and urgency for action and fight (lines 1, 3, 7 & 8). This also amplifies C1’s rights and the moral justification for action. Whilst C1 is embroiled in a personal narrative which indicates a moral dilemma, the sourcing of social permissions

elsewhere offer strong grounds for the acceptance of the opinions of an objective other. This mobilises agency and grounds for action.

C3 identifies key power figures in the form of important agencies that help to develop strength in the response of the first contributor, C1. To extend the battle metaphor further, this helps to develop a powerful army taking the form of ‘*Alzheimer's Society, Age UK, Carers UK, your M.P*’ and ‘*the law,*’ (lines 3-4).

Within the construction of a ‘fragile identity’ is an implicit suggestion of potential or actual resignation. This appears to have been responded to by the ‘fighter self’ resulting in the following emphatic plea, ‘*please do NOT give up,*’ (line 5). This authoritative instruction positions the ‘fighter self’ as in control, dominant and having influence over the ‘fragile self.’

The word ‘*enlist*’ (line 3) has connotations of enlisting as a member of the armed forces and invokes the identity of ‘fighter’. Furthermore, the suggestion that ‘*the law is on your side,*’ (lines 10-11) supports a justification of a ‘fighter identity’ to battle the professional other. This draws on the significant and powerful social institution of the law as an important authority member of the battle team.

The active nature of a battle is also reflected in how language has been constructed. There are more verbs used in the ‘fighter’ extract when compared with the ‘fragile self.’ The verbs are used to direct the ‘fragile self’ to act or to instigate action. ‘*Your husband must be removed,*’ (line 1), ‘*you must enlist*’ (line 3) ‘*they must take*’ (line 7). Furthermore, the choice of language also

reflects a slight distance from this action suggesting the ‘fragile self’ does not have to necessarily own the action, but they need to instigate it. In response to the ‘fragile self’ presented, it appears contributors are encouraging the individual to act through others. In addition, the short sentences and the directive language construction simplify the method of problem solving suggesting that this action is manageable to the ‘fragile self’.

C3 acknowledges the threatened, and therefore vulnerable, position of C1 and uses this as a tool to justify grounds for action. C3 directs responsibility towards the PwD, *‘His aggression and violence means he has violated HIS tenancy,’* (lines 9-10). However, there is a distinction between the portioning of responsibility towards the PwD when compared with the portioning of responsibility to other professionals. That is, whilst the PwD is drawn into the narrative as a significant blameworthy protagonist, the consequences and action taken as a result of this are static and merely serve to deflect blame from C1 and to justify action elsewhere. The dynamic battle is waged against the professional other and not the PwD as this is morally more palatable and justified. This ‘blame the system’ strategy has also been identified in discussion relating to asylum seekers (Goodman, 2008; Goodman & Speer, 2007).

Discursive devices are used by the ‘fighter identity’ to distance, encourage and develop a case for action particularly when speaking to a ‘fragile self’. The ‘fighter identity’ provides armour to the ‘fragile identity’ in order to develop a sense of agency and justification in action. Indeed, the interaction between the two identities is significant and potent as the analysis below suggests.

2.4.3. *'The Fragile self' responds to 'The Fighter self'*

The third stage of development within this interaction is presented in the response of the 'fragile self' to the 'fighter self.' The interplay between these two identities suggests the 'fragile self' is orienting to the idea of the 'fighter self' and is aligning themselves as a 'fighter.' The extract below follows directly on from the previous posts presented above.

Extract 7: (Day 2 of interaction after 2 days of no posting, 14th post)

C1, original contributor (see Appendix M for full extract).

1. *'Thanks X i am going to do this on monday hope all go's well as im*
2. *putting my foot down on this one'*

This extract presents a clear shift in C1's position when contrasted with extract 1. A sense of agency and ownership of action begins to emerge in the strength of the statement. The description reflects strength in the justified mobilisation of appropriate action. C1 has more agency and consequently appears more morally justified in her actions. However, there still appears some trouble in relation to this new position as C1 says *'hope all go's well'* (line 1). This also suggests that the experience of putting her foot down is new and she does not know what to expect.

In the interaction that follows there is more gathering of evidence and support for C1's case, as the 'fighter self' armours the 'fragile self' with the facts and draws

upon the rights of C1 as well as the duties and responsibilities of the care system. The ‘fragile self’ is constructed further through drawing on risk, fear and the position of an underdog. This discursive work encourages and gives further permission for the ‘fragile self’ to act, developing her sense of agency in allowing her to stand her ground. The interplay between the two identities creates an implicit moral dialogue of rights and duties that enables the explicit alignment of the ‘fragile self’ with the ‘fighter identity’ as presented in extract 8 below.

Extract 8: (Day 4 of interaction after 1 day of no posting, 29th post)

C1, original contributor

1. *‘.....he his now well enough to come home to which i replied he cant*
2. *come back here mind i think there trying to pass the buck back to me*
3. *but like you all said im standing my ground she said they are applying*
4. *for something from somewhere that allows them to deprive him of his*
5. *liberty to keep him in hospital...’*

The opening of the extract indicates that it has been argued that her husband is now well enough to come home. This is the point of battle as C1 states *‘he cant come back here’* (lines 1-2). This statement reflects a strong and almost defiant position held by C1. Indeed, the statement is particularly strong as no justification in narrative follows. Line 2 indicates potential threat to this position as it is suggested *‘there trying to pass the buck back to me’* (line 2). However, despite this threat the important sentence follows *‘like you all said im standing*

my ground' (line 3). This is a significant shift in position from the first extract. C1 has demonstrated how important the 'fighter self' has been in initiating change and action as C1 is now actively engaging with other professionals to allow potential change. Line 3 illustrates the strength of the group 'fighter identity' invoked in extract 4 and extract 6. C1 is drawing upon this group consensus and identity to justify her new position. The army of 'fighter self' was responded to. Line 3 again invokes the battle metaphor and indicates a strength in position that was not previously available to C1.

The shift in orientation of the 'fragile self' positions this identity as more malleable and unstable than the strong and robust 'fighter self.' It is interesting to note how the qualities of the 'fragile self' are realised and replayed in interaction. The 'fragile self' does not hold their position but a shift is influenced by a dominant other.

In exploring the interaction of these identities, it appears the 'fragile self' attempts to work hard to construct and maintain their moral character. Inevitably, at times during the identity of 'fragile self' a troubled moral picture is indicated as in drawing on the identity of a 'good carer', an identity of 'bad carer' is implicit. This invites a negotiation of blame and accusation in relation to the 'fragile self' and the management of a moral self in the presence of others. This social and moral work invites the strength and action of the 'fighter self' that facilitates the preservation of moral self within the 'fragile' caregiver. Ultimately, as a result of the challenge of the 'fighter self', the 'fragile self' is able to present herself as being more assertive.

2.5. Discussion

2.5.1. Summary of the findings

The analysis highlights the extensive discursive work relating to the construction and function of identity in dementia caregivers' talk. The identities of 'fragile self' and 'fighter self' emerged as prominent within the data and their construction and interaction performs a number of discursive achievements. Most evident is the discursive work undertaken within and by these identities in relation to the protection and presentation of caregiver's moral character.

The 'fragile self' is invested in seeking help and support and also in protecting the speaker's moral character as being a 'good carer'. The 'fighter self' is invested in offering supportive challenge to the 'fragile self' with this identity achieving further discursive work in the preservation of the 'fragile self's' moral integrity. Lastly, but importantly, the interaction between these two identities results in a shift in orientation from the 'fragile self' to a 'fighter self.'

2.5.2. Discussion relating to literature

The current study moves the exploration of identity in dementia caregivers forward from a focus on what identity *is* (Cadell & Clare, 2009) to exploring and understanding *how* it might be used in caregiver's everyday interactions. Unlike previous discursive research contributions in the context of dementia care (Forbat, 2003; Adams, 2000) the current study develops knowledge of how

identity is used by exploring interactions specifically between dementia caregivers. Furthermore, rather than focusing on identity work in relation to processes of social exclusion (Adams, 2000) or relationship difficulties (Forbat, 2003) the findings of the current study suggest the potential benefits of identity exploration to the caregiver as facilitated and shared within peer interactions.

Whilst the identity of the caregiving spouse has received some empirical attention from discursive researchers, this data has typically been ‘researcher provoked,’ (Forbat, 2003; Adams, 2000), with some research lacking an explicit and robust approach to discourse analysis (Hepburn et al., 2002). The current study develops understanding of the authentic everyday interactions between dementia caregivers (Perkins, Whitworth & Lesser, 1998) through exploring discursive practices that publicly construct and manifest the social self in everyday interaction. Findings suggest how the naturally occurring discourse between caregivers may facilitate credible and supportive challenge to a disempowered sense of self. Indeed, whilst reciprocal communication within the care dyad becomes compromised as dementia progresses (Laursen & Hartup, 2002) the current study indicates the possible benefits to the caregiver of engaging in reciprocal interaction elsewhere.

In the current study a supportive call to action from the ‘fighter self’ constructed a moral battle against the care system. Previous discursive research has identified a ‘battle and fighting discourse’ in dementia caregiver’s language suggesting problematic access to care services (Peel & Harding, 2013).

However, the findings of the current study develop understanding of how this

discourse may be harnessed by dementia caregivers and what it may be used to do in interaction. The dynamic and adaptive use of the ‘fighter self’ identity in the battle discourse offers supportive challenge, attempts to maintain moral character and allows criticism of care professionals. The discursive work achieved within this discourse encourages an orientation to a more agentic identity that may have benefits for dementia caregivers invested in the discourse. Indeed, agentic identity encourages the possibility of initiating action, the benefits of which have been identified in other research (Henman, 2014; Gunnarsson, Hemmingsson & Hydén, 2013)

Dementia caregivers’ supportive interactions in the current study reveal the emergence of moral identities. Caregivers draw upon the moral dimensions of ‘good carer’ and ‘bad carer’ throughout interaction. This builds upon work conducted by Forbat (2003) revealing the use of moral dimensions of ‘good carer’ and ‘bad carer’ in the context of identity construction and relationship difficulties between a caregiver and PwD. The current analysis focuses on identity work in relation and connection to the caregiver only, which offers the potential for the dementia caregiver to acknowledge and explore positive and negative identities specific to them as a caregiver.

The use of identity in dementia caregivers’ language has been evidenced in previous explorations both in spoken (Adams, 2000; Forbat, 2003) and written discourse (Kirsi, 2000). However, there has been no previous research exploring the construction of dementia caregiver identity online and as a result this research provides new and specific knowledge to develop the understanding of dementia

caregiver identity. Indeed, as the potential for using the internet as a supportive tool is ever increasing, it is important to understand the use of caregiver identity in online interaction.

The particular landscape in which the identity of the dementia caregiver is drawn is set within a unique and interesting social context. Unlike other online communities where the discursive currency of identity has been explored (Horne & Wiggins, 2009; Lamerich & te Molder, 2003; Giles, 2006) the identity of the dementia caregiver is not chosen but is entirely contingent on the caregivers social relations with the PwD. This may account for the amount of moral work that is undertaken in this interaction.

Caregiver identity is not associated with pathology as with other online identity research (Horne & Wiggins, 2009; Lamerich & te Molder, 2003; Giles, 2006).

The current findings highlight the potential positive impact of everyday interaction as an accessible and sustainable support to facilitating important and inevitable identity work in dementia caregivers.

2.5.3. Methodological limitations

The interaction explored in this analysis and the data set as a whole are predominantly representative of the discourse of female caregivers. Whilst this is reflective of a trend in the wider literature (Robinson, Bottorff, Pesut, Oliffe & Tomlinson, 2014), it is important to explore the discourse of male caregivers.

This could be achieved through focusing on existing discourse of male only

caregivers or through generating research data from a male only dementia caregiving sample. Furthermore, it is important to note that the social interaction under investigation was taken from an online forum and therefore it only reflects the discourse of dementia caregivers who are able and have chosen to access online support facilities. Further discursive research in this area would benefit from exploring the construction and function of identity in other individual or group support settings.

The findings of the current research are context bound to the specific interaction under analysis. That is, if the discourse had been between male caregivers in a focus group, the construction and function of identity would likely have been different. However, it is important to acknowledge, that whilst generalisations cannot be made, the findings of the current research do have resonance with previous research as explored above.

2.5.4. Future Directions

The family care dyad is the site where the most frequent and influential social interactions are likely to occur between the caregiver and the PwD. Exploration of the exchanges within this social relationship in relation to identity would provide a valuable insight into these important everyday interactions, some exploration of which has been introduced by Forbat (2003). Furthermore, interactions between formal caregivers and the PwD also invite attention concerning the construction and use of identity in interaction. Future research could explore the differences in discourse as relating to identity, between the

family care dyad and the formal care dyad (e.g. professional caregivers and PwD). This research is particularly important given the potential for identity to influence the position of these social agents in discourse.

In view of the influence that the ‘fighter self’ had on the ‘fragile self’ and the strength and agency of the ‘fighter self’ in the current study, it would be useful to explore whether not only the presence but also the influence of this identity is apparent elsewhere. This could be achieved by applying a discourse analysis to the interactions of dementia caregivers with care professionals to explore whether the ‘fighter self’ is apparent, how it is used, and what it achieves in this interaction. Such research would help to clarify the utility and potential benefit of the ‘fighter self’ in relation to caregivers’ interaction with care services.

Furthermore, in light of the contrast between the two identities within the current analysis, a comparison of the accomplishments of a ‘fragile self’ and a ‘fighter self’ in interaction with care professionals could also provide useful information in relation to what these identities may achieve in real and practical terms. In addition, how care professionals respond to caregivers’ identities is an important area for further research especially in view of the criticism of the professional other by both the ‘fragile self’ and the ‘fighter self’ in the current analysis.

2.5.5. Implications for clinical practice

The finding of the current study relating to the ability of the ‘fighter self’ to persuade the ‘fragile self’ into a position of greater agency could be beneficial to

both the ‘fighter self’ and the ‘fragile self.’ Indeed, the sharing of dementia caregivers’ interactions can influence the narrator and the audience and may have therapeutic benefits to both (Benbow et al., 2009). The use of identity in dementia caregiver discourse may be used to develop ‘identity-enhancing’ environments (Simmons-Mackey & Ellman, 2011). Specifically, that a context can be provided to caregivers that facilitates the expression of interactions and where caregivers can both construct and experience different identities. Such environments are likely to offer a means of identity exploration whilst peer support and validation is likely to be critical to this process as the current analysis suggests.

As the findings indicate, caregiver groups have an important role in validating, supporting and potentially shifting caregivers’ subject positions through interaction and exploration of alternative identities. These environments may facilitate peer interactions that enhance positive identity for the caregiver or positive identity shift, as evidenced by the orientation of the ‘fragile self’ to the ‘fighter self’. Furthermore, in the context of service provision these peer interactions offer accessible and sustainable intervention.

In the current study, the use of a ‘generalised other’ (Holdsworth & Morgan, 2007) enabled criticism against the care system. This may present an opportunity in the context of caregivers’ evaluation of services. Questionnaires and interviews or other data collection tools may benefit from situating the service and care professionals under evaluation as a ‘generalised other.’ This

may place caregivers in a discursive position that enables criticism of the care system which may otherwise be difficult for caregivers.

Care professionals and in particular therapists may be able to consider the use of dementia caregivers' identity in relation to the potential to communicate difficulties in vivo. This may facilitate an understanding of the caregiver and the caregiving relationship through focusing on how identities are constructed and resisted in live social interaction. Rather than trying to abstract meaning and interpret caregivers' talk, more attention could focus on the social action of caregivers' talk in relation to identity.

2.5.6. Conclusion

This study offers a valuable contribution to the understanding of identity in dementia caregivers. In particular, it has enabled a better understanding of *how* identity may be constructed by dementia caregivers and *what* identity can achieve in interaction. Identities have been shown to be malleable interactional devices, used to achieve particular ends; in this case appealing for sympathy ('fragile self'), calling for action against perceived injustice ('fighter self') and presenting and protecting moral character. Such discursive accomplishments have the potential to facilitate identity exploration and adaptation in dementia caregivers through everyday interactions.

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Chapter Three: Reflective Paper

‘Reflections on the Challenges of Conducting Research as a Mother’

In preparation for submission to *Reflective Practice* (see Appendix C for Author Instructions)

Overall chapter word count (excluding references): 2 399

3.1 Abstract

This chapter provides a reflective account of my experiences of producing this thesis. I offer a reflective account of my experiences in relation to the impact of conducting this research. In particular I focus on my experience of being a mother in relation to feelings of guilt and shame within the struggle of managing multiple identities.

Keywords: Clinical psychology; research; reflections; identities; emotions

3.2. Introduction

Reflective practice is viewed as a critical focus and attention on experience, inviting self-awareness and curiosity in one's actions (Cushway & Gatherer, 2003). It is suggested that this continuing and active process, aids the development of clinical awareness, clinical wisdom and life wisdom (Staudinger, 1999). In light of this, the current chapter aims to offer a curious exploration of my experiences of this research process. I reflect upon my emotional landscape during this time, with reference to my experiences of guilt and shame in relation to managing multiple identities. There have been interesting parallels between the content of this research and the process of writing it, and my own personal experiences as a mother throughout the conception, labour and delivery of this thesis (my second child!), which I will now explore.

3.3. Transitions

Following a period of maternity leave with my young son, the significant identity shift from 'mother' to 'trainee clinical psychologist' was hard. Indeed, framing it as a shift is problematic and overly simplistic as ultimately an assimilation of multiple identities and a process of social readjustment was required. Upon returning to my research, my identity as a 'mother' was well developed and active whilst my identity as a 'trainee clinical psychologist' had been more dormant. I needed to re-ignite this identity and assimilate it amongst others. I was exceptionally ambivalent about engaging with both these identities in synchrony and I found this at times, painful and challenging.

When an identity is contingent on a dependent other, (such as apparent in the role of parent or carer) particular challenge appears to present in relation to the maintenance of such identities amongst a multiplicity of other social roles. This connects to demands both internal and external alongside inevitable experiences of compromise and moral conflicts. Indeed, this has been explored in relation to dementia caregivers within both the literature review and empirical work of this thesis.

3.4. Multiple Identities

3.4.1. Moral dimensions

Identities of ‘mother’, ‘wife’, ‘friend’, ‘daughter’ and ‘sister’ (to name a few!) were all compromised and strained throughout the research process as my identity as a ‘researcher’ became increasingly dominant. I began to acknowledge the significance of the conflicting demands of these identities in relation to my emotional experience. Indeed, this was ever changing in relation to my research and my view of myself. This presented moral dilemmas most notable in relation to the inevitable conflicts between work and home life. Such conflicts were felt most acutely during times when my son was unwell or I was working on the weekend. It was rare that I felt I was doing well across more than one identity. If I was being a ‘good researcher’ then I felt I was a ‘bad mother’ and vice versa.

This reminded me of the ‘good carer/bad carer’ moral dimensions drawn upon by dementia caregivers in my research. For me, it felt like the moral charge of the role of ‘mother’ meant that I could only be a ‘good mother’ or a ‘bad mother’ and if I was not a ‘good mother’ then I *was* a ‘bad mother’. However in time, I learnt that this was not the case and was more reflective of my own ideals (perfect mother) vs. anxieties (bad mother). At times all I needed to be was ‘good enough’ (Winnicott, 1988) which neutralised the potency of my own self-attack. As Winnicott (1988) suggests, ‘...*a mother is neither good nor bad nor the product of illusion, but is a separate and independent entity...*’ This made me think about the ‘good enough carer’ and the potential use of this concept in relation to the management of caregiver burnout (Etters, Goodall, & Harrison, 2008).

3.4.2. Competition

At times it felt as though my thesis was a ‘greedy’ second child. Indeed, the conception of the idea, through to labour and then delivery signified a gradual increase in energy and attention required of me. This meant an increasing absorption into the identity of ‘researcher’ whilst less of an absorption into my identity as a ‘mother’. Indeed, I was aware of a constellation of different identities and their competing demands. However, even though I was more fully engaged with the identity of a ‘researcher’ I did not lose my identity as a ‘mother’. I learnt that identities are not either/or, but both/and.

3.4.3. Co-construction of identity

My identity exploration and development during my return to work and re-engagement with research, was inextricably linked to interactions with others, such as within the social context of family, friends and work. This made me acutely aware of how social identity is intrinsically related to social interactions, and is co-constructed within this context. I noticed how the identity of others changed as mine did and vice versa. This was particularly evident in relation to my husband as he began to spend more time with our son as well as completing more housekeeping duties as the demands of my research increased.

3.5. Guilt and Shame

3.5.1. Impact of behavioural expression¹¹

There are similarities between my experiences in relation to my son's tantrums and what I found in my literature review in relation to dementia caregivers' experience of guilt and shame. Indeed this, and the following sub-heading, map onto headings in my literature review in relation to dementia caregivers experience of challenging behaviour expressed by the person with dementia (PwD).

I became aware of experiencing guilt when my son was expressing his feelings through his behaviour that may or may not have been owing to my increasing

¹¹ Links to theme of '*impact of behavioural symptoms and expression*' of PwD in literature review

level of absence. However, my punitive superego (Lemma, 2003) would become active and I would assume responsibility for his behaviour, '*It's my fault I cannot sort it and make it better! It is my fault as I am not there enough!*' Rationally, I could acknowledge that he was an eighteen-month old little boy having one of many inevitable tantrums. However, given the opportunity and a constant feeling of '*not being there enough*' it was easy to launch an attack on myself.

3.5.2. Negative feelings towards cared for¹²

I became more aware of difficult emotions I was experiencing towards my son as a result of his behaviour, and this was catalytic to an experience of overwhelming guilt. Indeed, '*I should not feel angry towards my son as it is my fault!*' It is exceptionally hard to become aware of negative feelings towards someone dependent on you or vulnerable. As a result significant feelings not only of guilt but also of shame arose within me.

Shame appeared to be most identifiable when my son's tantrums were in view of his childminder. I shaped his childminder into a 'punitive other' and I felt criticised by her. In reality the childminder had said nothing to me, and I had no idea what she may or may not be thinking. It was interesting to note how I had viewed the world as critical, when actually it was my own self-critical attack that had shaped this experience. What I noticed during these times was an overwhelming desire for the ground to swallow me up! I can see how the power of an enduring experience of shame results in a desire to withdraw from others.

¹² Links to theme of '*negative feelings towards the person with dementia*' in literature review.

I noticed that it was easier to label my feelings as guilt than it was to admit feelings of shame (as a result of the very nature of this social emotion being hidden). As my research progressed and time went on, I began to make attributions to my whole self as a failure which resulted in an experience of shame. Shameful of what I viewed as my 'failure as a mother.' This got worse as the distance between my ideal 'good mother' identity and where I perceived myself to be ('bad mother'), increased.

3.6. Reciprocity

The guilt I experienced in relation to my faltering identity of 'wife' and 'friend' was not pleasant, but was far more bearable than when I perceived my identity as a 'good mother' to be faltering. This was interesting and it made me think about the differences of these identities and what it was about the role of 'mother' that evoked such considerable moral, emotional and social preoccupations.

I was able to talk to my husband and my friends about why I was not seeing them or able to be there for them as much and felt they were able to understand this. However, I was unable to talk to my son and explain the situation and he was unable to verbalise his frustration to me about my altered availability. My anxieties were that I was getting it wrong, I was a 'bad mother' and that I was not able to make it better.

The impact of this compromised clarity of communication made me think of caregivers caring for a PwD, particularly in the later stages and how this challenge to reciprocal communication may fuel the intensity of an experience of guilt. The opportunity to repair, as can be the healthy consequence to an experience of guilt, is interrupted. I was particularly mindful of this in relation to decisions concerning long-term care needs of the PwD. Indeed my literature review raises this as particularly catalytic to an experience of guilt.

3.7. Dependency

Some of the differences between identities such as those of ‘mother,’ ‘wife’ or ‘friend’ relates to the level of dependence and needs of the other person within the social relationship. My little boy is dependent on me as his ‘mother’, a big responsibility! There was less urgency of need relating to my husband, friends and others as they were not dependent solely on me.

This made me think about adult-child caregivers to a PwD. My literature review found that this group were particularly prone to an experience of guilt. Indeed, the weight of responsibility and the significance of another’s dependence is demanding. Whilst I do not wish to suggest that caring for a PwD is akin to parenting a child, what is similar, is the dependence of the PwD on their carer, particularly as dementia progresses. The experience for the adult-child caregiver with young children I believe would be particularly demanding owing to the responsibility of this dependence and urgency of need being apparent within more than one social relationship.

3.8. Protective Factors

3.8.1. Emotional Containment

The importance and significance of social relations and intimate connections became critical. My husband was a solid and reliable figure of support throughout this process. He was able to offer some 'head space' when I was full. In doing this, a parallel process allowed me to gain more space and think more clearly about my feelings. Whilst I still acknowledged the guilt was there, I was able to think about why it was there. This space allowed for the ability to repair my connection with both myself and consequently my son. It was simply but critically an emotional containment that allowed a shift in position giving me space to do something differently.

This made me think about the importance of social relationships that offer the opportunity for identity exploration for caregivers. Indeed, as my empirical paper suggests, it would appear social communication is critical to acknowledging, understanding and potentially changing difficult experiences or situations.

It was important for me to engage in personal therapy from the start of training as a clinical psychologist. Indeed, this has scaffolded my personal development throughout both clinical training and this research process. My understanding of my own experience of guilt and shame in relation to my past experiences and relationships was important for me to hold in mind throughout. Guilt and shame

are familiar emotions for me, and I believe this is largely why I was drawn to this area of research. However, this awareness allowed me to hold in mind my vulnerabilities whilst also ensuring I maximised the use of protective factors, such as support from my husband, to process these difficult experiences. Indeed, in talking about feelings of guilt and shame, these emotions become a less hidden internal experience allowing the opportunity to be managed differently.

3.8.2. Self management

Another way of self managing these conflicting identities and self-conscious emotions came from a mindfulness approach, adopting the view that ‘I can only be where I am in that moment’ (Kabat-Zinn, 1994). This also encouraged a more compassionate approach to myself. I would not say, by any means that I achieved this self compassion but a gentle turning towards it helped me to find pockets of respite from a punitive superego.

3.8.3. Time for reparation

The hope and longing for the opportunity to wholeheartedly connect back with my family and in particular, my little boy, has been significant. I recognise that this opportunity is now close and that it does exist (as I write my little boy is outside laughing in the sunshine of the garden with his Daddy and I look forward to joining them soon). I feel this has helped me to manage my considerable feelings of guilt throughout this research process. Inevitable compromises and sacrifices have been made but the reparation will truly be marvellous!

3.9. Conclusions

Caring for a dependent loved one ignites difficult feelings and conflicts within a constellation of different and competing identities. The responsibility of caring for a dependent is significant whilst the moral sense of duty and obligation it ignites is profound. A desire to do the best for the care recipient can easily become a pressure to be the 'perfect carer' - a fantasy that results in inevitable failure and inevitable feelings of guilt at not being able to do a 'perfect job'. My own experience of guilt and shame throughout the writing of this thesis appears to have been generated by a punitive and self critical attack on my propensity to engage with different identities with competing demands at different times.

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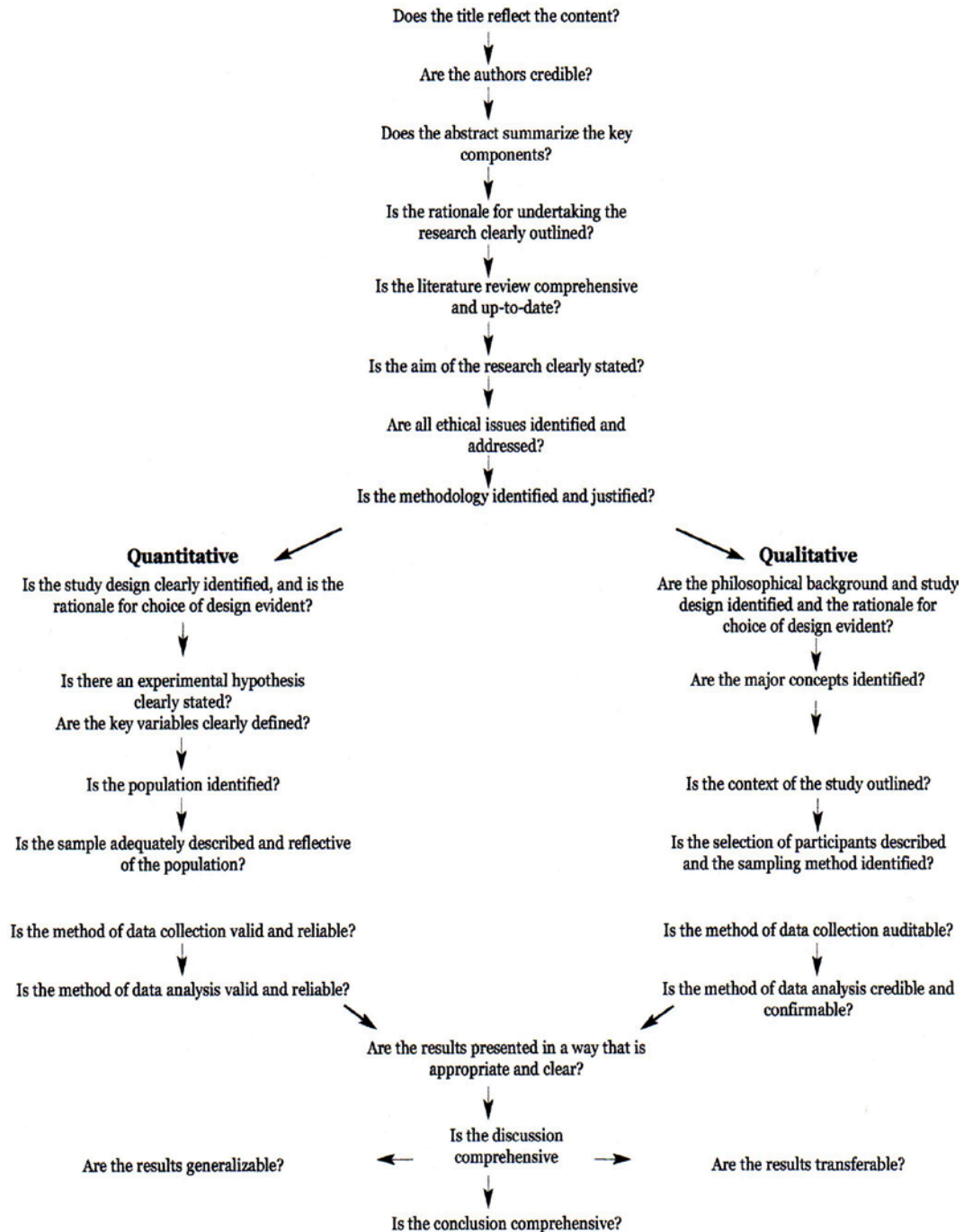
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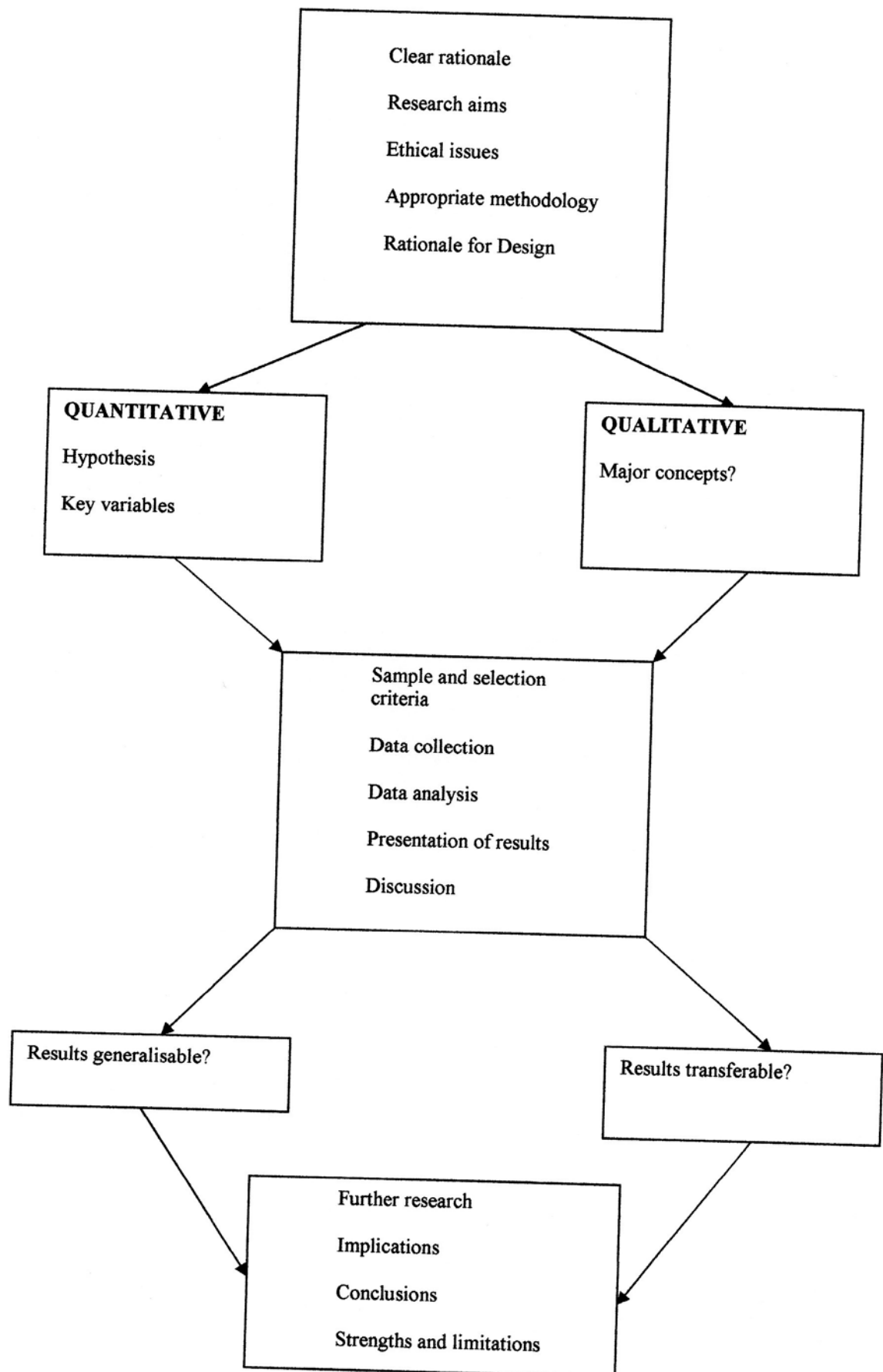
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Appendix D. Original quality framework



Caldwell, Henshaw, & Taylor (2005).

Appendix E. Flowchart to show adapted Quality Assessment Framework



Appendix F. Guidelines for quantitative quality assessment

Quality Assessment Criteria	Questions to consider
Clear rationale	<i>Are explicit reasons given as to why the research is being conducted? Does the evidence base support the rationale? Is the research justified?</i>
Research aims	<i>Is it clear what the author is setting out to research?</i>
Ethical issues	<i>Has ethical approval been sought/gained? Has the researcher acknowledged and considered ethical issues of consent/confidentiality/anonymity/ right to withdraw or any other ethical issues raised in relation to the research?</i>
Appropriate methodology	<i>Is the use of methodology appropriate for addressing the research aims?</i>
Rationale for design	<i>Is the design employed in the research made clear? Is there a justification offered for the choice of research design?</i>
Hypothesis	<i>Is the hypothesis clearly stated?</i>
Key variables	<i>Are key variables identified?</i>
Sample and selection criteria	<i>Is the sample adequately described? Is the use of the specific sample appropriate? Are recruitment methods described? Are exclusion/exclusion criteria made clear?</i>
Data collection	<i>Does the author describe the data collection process? Are the measures used appropriate, reliable and valid?</i>
Data analysis	<i>Does the researcher make clear which statistic tests were used and are these appropriate? Are confounding variables considered and/or controlled for?</i>
Presentation of results	<i>Are findings stated clearly? Are statistical data presented in a clear and appropriate way? Are significant and non significant findings made clear and differentiated between?</i>
Discussion	<i>Does the research summarise the main findings? Are these findings linked to existing research/theory? Are findings considered in reference to research aims?</i>
Results generalizable?	<i>Are the result generalizable?</i>
Further research*	<i>Are suggestions made for further research?</i>
Implications*	<i>Are clinical implications considered?</i>
Conclusions	<i>Do the conclusions accurately reflect the findings? Is the conclusion comprehensive?</i>
Strengths and limitations*	<i>Does the researcher offer adequate consideration of both strengths and limitations of the research?</i>

Appendix G. Guidelines for qualitative quality assessment

Quality Assessment Criteria	Questions to consider
Clear rationale	<i>Are explicit reasons given as to why the research is being conducted? Does the evidence base support the rationale? Is the research justified?</i>
Research aims	<i>Is it clear what the author is setting out to research?</i>
Ethical issues	<i>Has ethical approval been sought/gained? Has the researcher acknowledged and considered ethical issues of consent/confidentiality/anonymity/ right to withdraw or any other ethical issues raised in relation to the research?</i>
Appropriate methodology	<i>Is the use of methodology appropriate for addressing the research aims?</i>
Rationale for design	<i>Is the design employed in the research made clear? Is there a justification offered for the choice of research design?</i>
Philosophical background	<i>Is the philosophical background stated?</i>
Major concepts identified	<i>Are major concepts in the research made clear?</i>
Sample and selection criteria	<i>Is the sample adequately described? Is the use of the specific sample appropriate? Are recruitment methods described? Are exclusion/exclusion criteria made clear?</i>
Data collection	<i>Is the method of data collection auditable? Does the author describe the data collection process? Has the author included a copy of the interview script if applicable? Have issues of internal validation been considered? Biases? Reflexivity? Have issues of external validation been considered? Have there been attempts to enhance quality?</i>
Data analysis	<i>Is data analysis credible and confirmable? Does the author clearly describe data analysis? Is the issue of validity considered in the data analysis? Does the author offer sufficient support for findings with data?</i>
Presentation of results	<i>Are findings stated clearly? Are themes/subthemes clearly distinguished?</i>
Discussion	<i>Does the research summarise the main findings? Are these findings linked to existing research/theory? Are findings considered in reference to research aims?</i>
Results transferable	<i>Are the result transferable?</i>
Further research*	<i>Are suggestions made for further research?</i>
Implications*	<i>Are clinical implications considered?</i>
Accurate conclusions	<i>Do the conclusions accurately reflect the findings? Is there a clear link between results and conclusions?</i>
Strengths and limitations*	<i>Does the researcher offer adequate consideration of both strengths and limitations of the research?</i>

Appendix H. Quality assessment scores for quantitative papers

QUANTITATIVE RESEARCH PAPERS								
Quality Assessment Criteria	Quality Ratings: 0- Criteria were not met 1- Criteria were partially met 2- Criteria were met							
Articles	Conde-Sala, 2010	Losada, 2010	Martin, 2006	Parks, 1991	Roach, 2012	Romero-Moreno, 2013	Rudd, 1999	Werner, 2011
Clear rationale	2	2	2	2	2	2	2	2
Research aims	2	2	2	2	2	2	0	1
Ethical issues	2	2	2	0	0	2	0	2
Appropriate methodology	2	2	2	2	2	2	1	2
Rationale for design	2	2	1	1	2	2	0	2
Hypothesis	2	0	0	2	1	2	2	2
Key variables	2	2	2	2	2	2	2	2
Sample and selection criteria	2	2	2	2	2	2	2	2
Data collection	2	2	2	2	2	1	2	2
Data analysis	2	2	1	1	2	2	2	2
Presentation of results	2	2	2	2	2	2	2	2
Discussion	2	2	2	1	2	2	2	2
Results generalizable?	1	2	1	0	1	2	1	2
Further research*	1	2	2	0	2	2	2	2
Implications*	2	2	2	2	2	2	2	2
Conclusions	2	2	0	1	2	2	2	2
Strengths and limitations*	2	2	1	0	2	2	2	2
TOTAL (Max-34)	32	32	26	22	30	33	26	33

Appendix I. Quality assessment scores for qualitative papers

QUALITATIVE RESEARCH PAPERS							
Quality Assessment Criteria	Quality Ratings: 1. Criteria were not met 2. Criteria were partially met 3. Criteria were met						
Articles	Boykin, 1995	Forbes, 2000	Garity, 2006	Gessert, 2001	Hognes, 2013	Karlin, 2001	Navab, 2013
Clear rationale	0	2	2	2	2	1	2
Research aims	2	2	1	2	2	1	1
Ethical issues	0	1	2	1	2	0	2
Appropriate methodology	1	2	1	2	2	1	2
Rationale for design	0	2	0	2	1	1	2
Major concepts identified	0	2	2	1	2	0	2
Sample and selection criteria	1	2	2	1	2	1	2
Data collection	1	2	1	1	2	1	1
Data analysis	1	2	2	2	2	1	2
Presentation of results	1	2	2	2	2	2	2
Discussion	1	2	1	0	2	1	2
Results transferable	0	1	1	0	0	0	1
Further research*	0	2	2	1	2	0	2
Implications*	1	2	2	2	1	0	2
Conclusions	0	1	0	1	2	0	2
Strengths and limitations*	0	0	2	1	1	0	2
TOTAL (Max 32)	9	27	23	21	27	10	29

Appendix J: Research proposal submitted to Alzheimer's Society

Application for research partnership

Alzheimer's
Society

Leading
fight against
dementia

All applicants please note:

- The principal investigator must be sponsored by a recognised higher education learning institute (eg. a University)
- The principal investigator must be studying at PhD level OR has already achieved a PhD Or higher Clinical qualification
- The project must have received ethics consent
- The project must be of local interest and show benefit or value to the Society
- The applicant must prove sufficient experience of working with vulnerable adults, knowledge of the intricacies of working with people with dementia and/or their carers and empathy towards the challenges associated with living with dementia.

Please attach with your application form:

- Proof of CRB clearance for working with vulnerable adults
- Any additional information which will enhance your application.
- ALL attachments and supporting documentation and the final letter of consent.

Date submitted:

Principal Applicant		
Title and full name	Mrs Samantha Lowry	
Institution	Coventry and Warwick Universities	
Post held	Trainee Clinical Psychologist	
Department and address	Coventry University, Clinical Psychology Department Priory St, Coventry, CV1 5FB	
Contact details	Telephone 07793205003	Email bowyers2@uni.coventry.ac.uk
If you are a student please state the degree you will attain on completion of this research project	The research project is in partial fulfilment of a doctorate in Clinical Psychology	
Please list other applicants and institutes involved in the application	Applicant	Institute
	Dr Tom Patterson ¹	Coventry University & Coventry and Warwickshire Partnership Trust
	Dr Judith Bond	Coventry and Warwickshire Partnership Trust
	Jane Muers	Coventry University
	Dr Simon Goodman	Coventry University

¹ Changes to the research team were made and Alzheimer's Society were informed

Research title	An exploration of the care giving relationship within the context of dementia: A Discourse Analysis					
Does this research have ethics approval from NRES?	No IRAS is not applicable If yes, please include a full scanned copy of the IRAS application including ALL attachments and supporting documentation and the					
Research dates	Start date: May 2013			Finish date: Jan 2015		
Participants (please circle all that apply)	Staff	Volunteers	Persons with dementia	Carers	Family members	None ✓
Is funding allocated to supporting any costs incurred by the Society in the application	No					
Have you contacted anyone within Alzheimer's Society about the proposal?	Yes If yes, please provide contact details and dates Katherine Watt was emailed on 13/02/2012					
Are there any conflicts of interest? (eg. do you work or volunteer at the Society)	None					
How specifically do you hope the Alzheimer's Society will be involved and when do you expect involvement to start and finish?	The current research proposal is aiming to use data from the 'Talking Point' forum. Alzheimer's society will not be required to be actively involved in the project. The actual analysis will take place between May 2013 and July 2014.					
Why do you consider the Alzheimer's Society to be an appropriate partner for your research proposal?	The data from the 'talking point' forum offers a unique and naturalistic data set in order to explore using a discursive approach, how carers of people with dementia talk about their experiences.					

Please detail your experience working with people with dementia or other vulnerable groups?

Clinically I have worked with people with dementia and their carers on a 6 month Older Adult placement as part of the Clinical Psychology Doctorate I am currently undertaking. This placement was 3 days a week for 6 months at an Older Adult Psychology Service within Coventry and Warwickshire Partnership Trust. In addition, I also have my own family experience of a relative with dementia and consequently believe I have both professional and personal knowledge and experience of both the rewards and challenges of caring for a person with dementia.

I have also completed a 6 month Child and Adolescent Mental Health placement and an Adult Mental Health placement again working clinically for 3 days a week as part of the Doctorate course both were within Coventry and Warwickshire Partnership Trust.

As an Assistant Psychologist I worked within severe and enduring mental health with people with schizophrenia and bipolar disorder within a rehabilitation setting, working within Birmingham and Solihull Mental Health Foundation Trust. I worked here for 18 months on a full time contract.

I also spent 6 months working with children with autism within a project called UK Young Autism Project.

I have also worked as a research assistant at Coventry University, exploring factors affecting literacy in school age children.

Summary of project	Background
<p>Please include project aim and objectives, a detailed methodology (including recruitment, anticipated number and location of participants) and details of dissemination plans to a maximum of 1000 words</p>	<p>There is a dearth of qualitative research literature that explores informal carer's constructions of the caring relationship within dementia. In consideration of which, it is felt that discourse analysis offers a methodological approach to the current exploration that is sympathetic to the values of person centered care (Kitwood, 1997). The approach allows consideration of social action within the caring relationship and consequently addresses a methodological blind spot in the current research in this area.</p>
<p>Please attach all appropriate documents with your submission including;</p> <ul style="list-style-type: none"> - consent forms - information forms - questionnaires - interview templates 	<p>Older adult use of online resources has begun to grow, (Ofcom, 2011). The number of internet based research studies within the field of older adult psychology is however minimal. Researchers such as Potter (1997) consider the data that internet resources such as internet forums can offer to the researcher is more natural and less contrived than other means of data collection.</p>
	Aim
	<p>The main aim of the proposed study is to explore how carers who contribute to an open internet dementia support forum talk about the caring relationship within the context of dementia.</p>
	Implications
	<p>It is hoped that the research may help to increase understanding of the difficulties experienced by those who care for people with dementia. Consequently this may offer new ways of considering how best to support carers to enable them to maintain the personhood of people with dementia. The research could be of value within both professional and public spheres, that is to health care professionals, dementia care services and voluntary sector services, whilst also offering people with dementia, informal care givers, and the wider public further information, understanding and awareness of dementia.</p>
	Methodology
	<p>The study will use a qualitative design using discourse analysis, (Potter & Wetherall, 1987). Specifically, discourse analysis does not attempt to gain an understanding of an individual's experience by inferring cognition. However, through analysing discourse it is possible to consider how that person may construct their reality within a particular experience through considering actions within discourse. Discourse can be understood to reflect a version of reality and discourse analysis as a method of approaching data such as text, conversation or dialogue to explore the ways in which the individual participant or speaker is constructing their reality.</p>
	Procedure
	<p>The study will aim to extract around 10 accounts of data (accounts will likely vary in size and will include a complete thread</p>

on the forum). However, this will involve reading more than 10 extracts initially. The forum data will be read through carefully in order to allow for consideration of whether the contributor to the forum is discussing aspects of the care giving relationship. Extracts from contributors who offer discussion of the care giving relationship will then be included for further analysis.

Data will not be amended or changed in any way by the researcher however, in order to offer clarity and precision to the analysis and to direct the reader to extracts within the text, the researcher will type out the extracts in a word document and will number each line of data.

Initially, data will be reviewed in order to code up the data so as to organise it into manageable chunks. The coding process requires a focusing on key aspects of the research questions, for example, any references within the discourse that are made to the challenges or rewards of caring for a person with dementia will be highlighted.

When analysing the data the researcher will be asking questions such as the following: What are the different identities that are taken up by the contributors? Who is this discourse aimed at/ who is the ideal reader? Who offers the discourse? What is not said in the text? How does the contributor present their experiences? What message does it appear the contributor is offering or intending the reader to take up? What repetitions might exist within the data?

Write up

The analysis will be written up and presented along with extracts taken from the forum data used to illustrate and support the findings of the analysis. The analysis will then be written up into a doctoral level thesis as a partial requirement for the Clinical Psychology Doctorate, DClin Psych, at Coventry and Warwick Universities.

Dissemination

The research study will be written up as a paper, which will be submitted to a peer reviewed journal with the aim of publication probably to *Dementia*.

Appendix K. Ethical approval from Alzheimer's Society

Watt, Katherine <KWatt@alzheimers.org.uk>

Thu 19/04/2012 16:35

Inbox

Hi Sam

Just heard back from our Quality team and they are happy with your form, so please do go ahead and post in the Researchers, Students and Professionals forum on Talking Point.

If you have any other questions about using Talking Point or need any more help from me, please let me know.

Best of luck with your research,

Katherine

Katherine Watt
Talking Point Manager
Alzheimer's Society
Devon House, 58 St Katharine's Way, London E1W 1LB
T: 0207 423 3533
kwatt@alzheimers.org.uk
alzheimers.org.uk
<http://forum.alzheimers.org.uk/index.php>
Leading the fight against dementia

Watt, Katherine <KWatt@alzheimers.org.uk>

Thu 19/04/2012 16:39

Inbox

Apologies Sam, I've just remembered that you won't in fact need to post on the forum, so please disregard that part of my email!

Best,

Katherine

Katherine Watt
Talking Point Manager
Alzheimer's Society
Devon House, 58 St Katharine's Way, London E1W 1LB
T: 0207 423 3533
kwatt@alzheimers.org.uk
alzheimers.org.uk
<http://forum.alzheimers.org.uk/index.php>
Leading the fight against dementia

Appendix L. Ethical approval from Coventry University

A discursive analysis of dementia caregivers online contributions to a support forum.

P15987

REGISTRY RESEARCH UNIT ETHICS REVIEW FEEDBACK FORM

(Review feedback should be completed within 10 working days)

Name of applicant: Samantha Lowry

Faculty/School/Department: [Faculty of Health and Life Sciences] Clinical Psychology

Research project title: A discursive analysis of dementia caregivers online contributions to a support forum.

Comments by the reviewer

1. Evaluation of the ethics of the proposal:

Based on the information provided, there are no serious ethical concerns, other than ensuring that due consideration is given to ensuring anonymity of data, treating the data sensitively and adhering to ethical principles of research that uses data available in open access forums.

2. Evaluation of the participant information sheet and consent form:

As the project involves analysis of online data from an "open" (public) forum, a participant information sheet and consent form are not required.

3. Recommendation:

(Please indicate as appropriate and advise on any conditions. If there are any conditions, the applicant will be required to resubmit his/her application and this will be sent to the same reviewer).

☒

Approved - no conditions attached

☐

Approved with minor conditions (no need to re-submit)

☐

Conditional upon the following – please use additional sheets if necessary (please re-submit application)

☐

Rejected for the following reason(s) – please use other side if necessary

☐

Not required

Name of reviewer: Anonymous.....

Date: 01/11/2013

I don't even know what to say, just wanted to let you know you will be in my thoughts. x
 WOW ~~you~~ you are amazing. xx *supports authority* *credibility of forum*
 I also think ~~your~~ *corroboration* *not general* *add* *push oriented*
 The only thing I wanted to add is: are you vacating your home because the LAs are insisting there should be a home trial but you don't feel safe with him there? The home trial thing isn't ~~useful~~ *useful* but if you are in fear, I would strongly suggest you contact the Alzheimer's Society helpline <http://forum.alzheimers.org.uk/faq.p...urces>, helpline and find out what your legal ~~options~~ *options* are. Because while his behaviour may be the result of his dementia, you also shouldn't be effectively tossed out of your home and nor should you live in fear. If he is dangerous to others (specifically you) he may need to be sectioned, or at the very least, placed in an assessment unit to see if there is any medication that might work.
 I'm sorry to hear about your situation.
 Lots of good advice has already been given and I thought I would just mention The Cinnamon Trust with regards to your dog.
 They offer help for animals that are unable to stay in their homes, using foster carers. Have a look at their website they are fantastic.
<http://www.cinnamon.org.uk/>
 Hope you can get sorted quickly, I hate to think you have to leave your home and be away from your dog.

Quote:
 I am so angry that I have to leave and my dog which will have to be found a new home as I need sheltered housing we both have names on the rent book it seems to me that I'm the one in the wrong I was sooooo upset tonight couldn't stop crying more for my dog than for me
 I am so sorry but with all your worries and troubles, the thing that is standing out for me is that sentence because I understand it so well. All the rest seems, absolutely, so very wrong and you have received good advice from ~~me~~ *me* and ~~James~~ *James* and I do hope that you are not ~~forgetful~~ *forgetful* of your home. Surely you can't be if your name is on the rent book. However, what happens if the SS later concede they were wrong but your dog has already been rehomed? My husband is in a nursing home so, I am alone with my dog. I dread the time when I lose her. I do so hope that you don't have to lose yours.
 Please fight for both you and your dog. You shouldn't have to be treated like this.
 I just don't get this, why would you have to leave your home, that is ~~disappointing~~ *disappointing*, I can not see why they couldn't let your husband stay in a care home. Please take ~~me~~ *me* advice, she is usually spot on. I would be contacting your MP, you should not be turned out of your home, you need someone to ~~act on your behalf~~ *act on your behalf*, I am so sorry you are being treated like this, sending you huge (!!) xx
 I'm list for words. ~~your~~ *your* post is spot on. I do hope you get things sorted out for yourself. x

Thank you all for your comments they have been helpful it was my decision to leave as he gets violent had to go in June for the same reason yes were in housing association joint tenants I was leaving as he was violent in are early marriage but mellowed as he got older couldn't go out or go on holiday no family get together totally controlled I was but we did get through it but this horrible lewy body disease has brought all of it back I have lasting power of attorney over health and welfare and finances I did ask if they could put in a nity but told me it was the law that they had to follow procedures to see if he could look after himself now I know he can't so do his doctor so I don't know why there doing this so I had no option but to find refuge at my nieces but can't stay there long as she has 5 children I mention mental capacity assessment didn't seem to want to go down that route he is actually in hospital now as when he went into respite he caught a very bad chest infection ever since has been in there has been wanting to come home and even didn't have last antibiotics as he kicked off and refused saying there was nothing wrong with him - sat on a car in the ward corridor with his bag packed so they rang me up and asked if I could come and calm him down to which I did with the help of his brother but then kicked off tonight when I went in on my own wouldn't let me go to the loo or leave the ward started threatening so I had to scramble up the ward quickly whereby he tried to chase me they had to restrain him so I could get of the ward to get home rang 2hrs later still wandering all round the ward they told me he had extra diazepam but hasn't helped im now frightened of him coming home which they said would be Monday as he has regressed back to when we were young I just can't go through those yrs again im 68 and serious health problems myself so im ring the ss lady first thing Monday morn to tell her that because of his worsened condition and my health he can't come home he had a chest infection for 3 weeks can't clear it im to low in myself and I know this is the start of the downhill of this disease need to know where I stand now on this one thanks everybody x
 Sent from my GT-N7000 using Talking Point mobile app

It is your home. Your husband must be removed and assessed.
 You and your darling dog friend do not need to go anywhere.
 You must enlist the support of an agency to help you, Alzheimer's Society, Age UK, Carers UK, you etc.
 Please do NOT give up and move into a place that means your dog has to be re-homed while they assess your husband.
 They must take him out of the situation where he is threatening you and assess him.
 It's nonsense for them to suggest that it must be done within his home.
 His aggression and violence means he has violated HIS tenancy.
 Please don't agree to this, you have the support of the law on your side.
 I am so sorry you are being treated like this, sending you huge (!!) xx

I am so sorry you are being treated like this, sending you huge (!!) xx
 I am so sorry you are being treated like this, sending you huge (!!) xx

your dog! *understand but*
attacking
then blow
7 similar!
what's up
a narrative
huffe

3 14th insure NOT AGENCY!
Thanks gamuff i am going to do this on monday hope all go's well as im putting my foot down on this one
Sent from my GT-N7000 using Talking Point mobile app

Elspeth
Yes Jennifer i really am in fear of him now has he has regressed back to when he was young he was doing it up the hospital tonight
Sent from my GT-N7000 using Talking Point mobile app

Elspeth
In a way, it's good that he was doing this at the hospital; you can point to that as evidence that he is danger to others, particularly you, if he is released from the hospital. You are going to have to be very clear and steadfast about this: you need to say quite clearly that you are in fear for your safety and life should he be released back to his home. You may well have to raise the subject of him being sectioned if they are thinking about letting him come home.
I say it again, you need to make it crystal clear that you are at real risk of physical violence and that you will hold whoever releases him legally responsible in the event you are injured.
fight fire with fire amplification
The or animal host

Quote:

Originally Posted by Elspeth

Thanks gamuff i am going to do this on monday hope all go's well as im putting my foot down on this one

Sent from my GT-N7000 using Talking Point mobile app

And so you should.

It is not up to you to vacate your property for them to assess him as obviously you can no longer live together for your own safety.

I think you will find that their views change when you next talk to them, now that they have independent evidence that he has violent tendencies and cannot be placed back home with you.

Again - it is not acceptable to ask you and your doggie to vacate your home under these circumstances.

Be polite but firm. It will work out ok for you.

explosive/bold & early

Hi please remember that you can also refuse to take him home from the hospital, they will have to section him, can't understand why they haven't after witnessing his behaviour to you. I would start the ball rolling today by calling the emergency social services number to put your case to them. What you don't want is the hospital transporting him back to your house. Good luck xx

Elspeth

In an odd way it's not altogether bad that he has kicked off at the hospital, at least independent people have seen how he turns. The hospital is duty bound to facilitate a safe discharge for your husband and if you tell the hospital staff in writing that you want a REACT team to assess him, then refuse to leave the house or help him, REACT will have to consider alternatives as it's not safe for you or him if they can't care for him.

Refuse to have him home these assessments can buy you another couple of weeks while you sort the rest of it out. I am surprised the hospital didn't consider sectioning him, have you spoken to the hospital about that possibility?

Bangor

I can't add much to the excellent advice you've already got here, but in addition to getting support from Alzheimer's society, it could also be helpful to talk to Women's Aid. As hard as it is to stand up for your rights when you are exhausted by caring, it is your home and you have the right not to be made homeless! Very best of luck - you deserve it!

Elspeth

Aww thank you every one didnt know about the react i will tell's lady in the morning has he was wandering the ward all night going into 2 lady's rooms and kept going to see a man cause he thought it was his brother didnt sleep alright they said i still ring to make sure hes out just didnt want to see him today because of what happened last night thought we would have the same problem but i phone this evening just trying to get him in to bed they said as he was exhausted hope he sleeps well why has this happened is it the chest infection being horrible to his lewybody dementia hes regressed back so rapidly its unbelievable hes was only diagnosed in 2011 this i think is unusual really such a short time! havent stopped crying yet cause of last night but got to tell the ss lady to get up there in the morning as there getting the hospital ss lady on it as well i do hope they can sort it so i can start calming down my chest still hasn't got right yet i think its the stress as well x

Sent from my GT-N7000 using Talking Point mobile app

Elspeth

Noora can you tell me what REACT stands for please so i have the information i like to know what im on about when i talk to these people thanks x

Sent from my GT-N7000 using Talking Point mobile app

Elspeth

Not REACT, but REACT = rapid emergency assessment care team

10:01 AM

Quote:

Originally Posted by ~~xxxxxx~~
Not ~~xxxxxx~~, but REACT = rapid emergency assessment care team

Thanks ~~xxxxxx~~, they assess the patients ability and home support network, they will arrange for adaptations to the home to make it safe before discharge. Things they have arranged for us are raised seats, raised toilet seats with bars to prevent falls, a wet room, commodes, hospital bed, a wheelchair. Mum has been ill for twenty years so these things have gone in gradually as her health has deteriorated. If they think a discharge will not be safe they look for alternatives.

In mum's case and I'd imagine most peoples' they wont discharge until the safety equipment is in place.

SAFETY

11:00 a/c
a/c

b. by p a care

10:14 AM

Just want to add my support to you at this awful time. At least you now have independent witnesses to his behaviour.

Please stay strong and refuse to have him home. Pass the responsibility to social services. They have a duty of care, you don't.

And remember, we're all behind you. Good luck for tomorrow.

strong in my!

10:29 AM

I am horrified and so worried for you.

Please stand up for yourself.

s-sports He understands.

You must keep on telling them you are in fear for your life. He cannot be allowed to come home.

Cry, scream and shout if you have to. This is serious. ^{extra care for} ^{aplastic}

xx ^{extra care}

names agency

extra care

11:02 AM

bold
case

I can only join the others in begging you to stay firm and say you can not and will not accept him home with you as you are in fear of what he may do to you. You must tell them he has reverted back to the abusive person he was in his younger days. You do have every right to refuse nobody can be forced to care for another adult and as the others have said you now have independent witnesses to his behaviour. I don't think it is the infection that has led him to revert back to his past behaviour, my Mum was never a violent aggressive person before the dementia with lewy bodies took over her, but this is exactly what she became. Keep us updated we will try to help you xx

before safe contact

insulting

11:20 AM

Quote:

Originally Posted by ~~xxxxxx~~
Just want to add my support to you at this awful time. At least you now have independent witnesses to his behaviour.

Please stay strong and refuse to have him home. Pass the responsibility to social services. They have a duty of care, you don't.

And remember, we're all behind you. Good luck for tomorrow.

Hello ~~xxxxxx~~, I also want to show my support & agree with ~~xxxxxx~~, you MUST pass the responsibility onto the S Services THEY HAVE a Duty of Care & they MUST not pass the buck to you or any body else

Hyperthermia
Stress

Wishing you much Love & Strength in the days & weeks to come

Love xxx

29th

fantastic work
RBM

02:46 AM

Update on Fred. They moved him yet again to the elderly persons ward today on which the social services lady rang me to ask me not to visit for a couple of days also to tell his sisters to do the same as he is kicking off big time she said she's got to go up there tomorrow to see what's what but he's now well enough to come home to which I replied he can't come back here mind I think there trying to pass the buck back to me but like you all said in standing my ground she said they are applying for something from somewhere that allows them to deprive him of his liberty to keep him in hospital as when I seen him yesterday with his brother we still had a job to get off the ward as he thought he was coming home it keeps on upsetting him by me going up there so im leaving a few days for him to calm down. I only hope they come to the right decision on this as its making me ill and I keep crying his sisters keeps on but really there not being helpful they keep saying "he just wants to come home" and "he was ok at christmas its so rapid" which I tried to explain sundowning and how this horrible disease can deteriorate quickly I told them ages ago to research it but no they just like to sweep it under the carpet. But now its come back to bite them so there trying to find ways to make it better just dont understand really so got tomorrow now to worry about not much sleep again tonight please wish me luck im so down

Sent from my GT-H0000 using Talking Point mobile app

stroke criminal

if it's
spect

02:59 AM

I do wish you luck, and I am really impressed that you are standing your ground about this. It sounds like they are taking the deprivation of liberty approach (Dols) which is appropriate (it basically enables a provider to stop a person from leaving a care situation).

My feeling about his sisters is: if they think he should come home they should take him to their home.

I understand why you feel down, but you are doing all you can do and, most importantly, it's not your fault: this is a ghastly illness. However, you don't have to be a victim, at least

Marty

MARTIN

5

respective know

Princess 66

as for physical assault, I'm sure you'll always feel responsible, but that's the guilt monster at work. None of us want to be in this position (dealing with dementia) but none of us should be put in a position where we are fearful for our safety

Caroline

I can't believe Fred's sister is insisting on going to see him when she was asked not to...what is wrong with her? Sounds like she really needs a wake up call...I agree with Jennifer...send him home with her! Keep strong and don't let ANYONE bully you including Fred and his family. Good luck...I will be thinking of you

03:16 AM

PRINCE

Betty → mother

bold
care!

Hiya Zippin

07:51 AM

One thing to keep saying to the likes of SW is...if the hospital can't control his behaviour with all the people they have around him then how do you expect me to even contemplate trying? Tell them no way are you even considering it as your health will not allow you to. The more he kicks off in hospital the better quite frankly as it just highlights what level of care he needs going forward.

PRINCE

validity strength

carbocation

10:22 AM

no
honest
strong
strong
strong
strong

Hi, I am so pleased you are being so strong and brave and standing up for yourself, I too wish you luck. I agree with Jennifer, if his sisters think he should go home then they should take him to their home, believe me they would not last a day with him. It is a terrible disease and you have not given up on Fred, you are getting him the help he desperately needs and the help that will enable you to visit him without the fear of his aggression, which you can no longer face alone. I wish his sisters would come on this forum and see for themselves that everybody has their limits to how far they can go caring alone. Keep strong and I hope this is resolved very quickly for you, hope you are feeling better very soon, keep posting, we will support you xx

Another here congratulating you on standing firm

Easy for us to say and harder for you to do I know but better for everybody in the long run. Do tell me you still have your dog.

11:25 AM

PRINCE

02:43 PM

Well done, just stay strong. My husband before going into a nursing home was admitted to an assessment centre and we were told he could not be come home his care was too complex.

He is now in a wonderful nursing home and needs 1:1 care 24 hours a day. The carers rotate on the floor every hour. There are 9 carers looking after 8 men on a 12 hour shift. So it takes all these carers to do the same job I was doing at home on my own.

It is not till you get to this stage that you realise just what you are doing and there is a limit to what should be expected. Stay strong, your husband has reached the stage where trained staff are needed to care for him and you need to draw breath and still care but not in such a stressed way.

life. still cover

PRINCE

02:18 AM

Thanks Jennifer yes your right that's what they were getting (dads) they have found him a placement now its a bit far for me but will go there to see him when he goes she is also getting what they call an IMCA person so they can deal with it better. All im worried about now is him keep being moved he will now go to this and then may have to move again this is when he kicks off big time But I do know this one has going to be run by the order of St John which is for the over 65s and has good reputation as there not for profit it looks really nice so that will settle me down knowing he will be safe I will put an update on when I've seen him tomorrow hopefully he wont kick off at me again but not hopeful our 50th wedding anniversary march long time the support we had until has been brilliant it was all my friends on here that I got through this and I can never thank you all enough xx

Sent from my GT-N7000 using Talking Point mobile app

stacey

02:45 AM

So your husband is being moved to a nursing home?

It sounds as if things are working out for the best, sad though it is for you after 50 years. I am so sorry, but hoping that he will settle and you can enjoy your visits with him soon.

Keep on keeping strong and remember there is no way you could cope with him at home.

xx

PRINCE

04:21 AM

I am so relieved that they have found him a placement. I'm not so happy that it isn't convenient for you to get to. Have you asked about the possibility of moving him closer to you if a place becomes available? You may not be able to cope with him in your own home, but you should be able to visit him without too many problems, as that's to his benefit, not just yours.

A decent nursing home will be able to manage his behaviour, so I wouldn't assume that they won't be able to cope with him if he kicks off.

PRINCE

08:23 AM

Hello, I'm so pleased :) the SW has found a NH for your Husband & yes you are right the Charity NH are often a lot better than the big firms that are just looking for big profits :)

Take care & sending positive vibes to you both the move into the NH goes smoothly

Much Love & Kind thoughts (& do hope you still have your dog?) I love dogs even tho do not own one

P5

Share exp

09:55 AM

That is good news. I'm sure it will all work out for the best for both you and your husband. You are following in my footsteps. My husband went into a nursing home in June 2011 and our 50th anniversary was 2 months later, in August. It was an odd way to celebrate a Golden Wedding. Only the previous summer we had been talking about how we might celebrate it but it was not to be. He didn't even know what the day was but I took in a cake which was shared around his wing of the home and he was allowed to have a piece - as a diabetic, a rare treat. So that was all it meant to him in this world. I hope you can now relax a bit after all your worry about where to live and losing your dog.

Page 1 of 2 1 2 ▶ Last »

Show 40 post(s) from this thread on one page

All times are GMT +1. The time now is 03:41 PM.

Alzheimer's Society Talking Point

Printable View

Page 2 of 2 #First 4 1 2

This is great news, I'm so relieved for you. It would be better if he was closer to you but perhaps that can be sorted out later as Fiona says. For the moment you have got the result you needed, thank goodness.

xx

~~Response~~

So pleased for you, it will feel really strange for you but there was no way you could have coped alone any longer. Just sorry it is a bit far for you, but this other place is a nice place and they are good perhaps it will be worth letting him stay there, visiting will then have to be as and when you feel up to it. I would think you just need to rest a while for now. Let him settle in a bit xx

~~Reply~~

~~Response~~

Angemg and collodge girl thanks i will settle when i know it will be permanent ive not rested yet as ive been going up the hospital on a daily basis of course his sisters as i expected only gos when there out and about together usually afternoons for all there anger at me saying its to far out to keep going there when hes in nursing home but i dont take any notice now they have no input as far as im concerned hes my husband so what i says gos ive only been able to do this from the help and advice ive had on here tp its been my savour thanks everyone fir your wise words and inspiration in the comments with out you my family of friends i would still be in the same position i was a month ago .. i will still keep in touch on here as i will let you know when bits final THANKYOU xx

Sent from my GT-N7000 using Talking Point mobile app

~~Response~~

And saffie i still have my miniture jack russell brilliant thanks x

Sent from my GT-N7000 using Talking Point mobile app

~~Response~~

Nice to hear your post this morning, you do sound so much more positive and you are right to ignore his Sisters you are doing what is best for your husband first and then yourself, so you are still putting him before your own health and wellbeing. I hope he settles in to nursing home soon and you are finally able to relax a little more take care xx

~~Reply~~

~~Response~~

Quote:

And saffie i still have my miniture jack russell brilliant thanks x

O I am so pleased to hear that. Long may she remain with you too. There's nothing like a good cuddle with a faithful doggy companion. Well done for all you have managed to do. I hope things continue to work out and, yes, do keep coming back here.

~~Response~~

I am as equally as delighted for you as I am horrified that anyone tried to get you out of your home and that without the advice from here, it might have happened. When your husband has settled, I'd seriously consider making an official complaint about whoever told you to do that.

~~Response~~

Angemg and saffie and neeze thank you all for all your help and advice and the others sorry if i spelt your name wrong as when you reply i sometimes forget . Yes i may think about a complaint actually as they put me through a lot of stress thanks xx

Sent from my GT-N7000 using Talking Point mobile app

~~Response~~

I don't have much to add, but I am keeping up with your thread. :) I'm so pleased you still have your dog: they are such a comfort.

~~Response~~

Congratulations on everything you have achieved in a short period of time. I hope your husband will settle in his new home and that you and the doggie can relax too knowing he is safe and being looked after.
You have achieved so much. Not many people these days stand up to those in power and get a resolution like this. You fought for what you knew was right not just for your but for your husband too!

hugs xx

<http://www.alzheimersociety.org.uk/talkingpoint/showthread.php?p=66455&app=alzheimer>

10/07/2014